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## Primary Care Provider Management of Anxiety and Depression in Palliative Patients

Colette Zunk  
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Primary Care Provider Management of Anxiety and Depression in Palliative Patients

Submitted by Colette Zunk

May 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

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## **Abstract**

Anxiety and depression are common psychological experiences in patients who have advanced disease and are often unrecognized and undertreated. This study examined how primary care providers assess, identify and treat anxiety and depression in patients who have advanced disease, as well as to illustrate to what extent social work and mental health services are currently being utilized to address these psychological issues. Primary care providers at two rural clinics in Northern Wisconsin were invited to participate in this study, including Family Practice and Internal Medicine Physicians, Nurse Practitioners and Physician Assistants who provide primary care to patients, including patients who have advanced stages of disease. Of these two clinics, one clinic is piloting a Patient Centered Home Model of patient care and the other is a traditional primary care clinic. Nine Internal Medicine and Family Practice Physicians, Nurse Practitioners and Physician Assistants from one rural medical clinic participated in this study using a one time, qualitative interview by means of a semi-structured interview format. Inductive grounded theory methods were used to analyze the data.

Several themes were identified in this study which supports previous research such as the need for additional physician education; lack of standard screening tools; and the issue of time constraints that affect the physician's ability to identify and treat anxiety and depression in palliative care patients. There were two surprise findings: one theme was that there was not a clear definition of palliative care, therefore affecting the identification of palliative care patients and the other was the high utilization and support for social workers in the primary care setting. The findings of this research support the need to implement social work services in the clinic setting to assist the primary care providers with many psychosocial issues including the emotional needs of patients who have advanced disease.

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## Primary Care Provider Management of Anxiety and Depression in Palliative Patients

Identifying and treating anxiety and depression is a very important issue for patients who have advanced diseases, yet these issues are often unrecognized due to a variety of factors. These factors include lack of adequate physician training, limited access to mental health providers, the challenge of sorting psychological distress from symptoms caused by the medical disease (fatigue, weight loss and sleep disturbances) and patients who do not identify themselves as being anxious or depressed (Lawrie, Lloyd-Williams, & Taylor, 2004; McQuaid, Stein, Laffaye, & McCahill, 1999; Pessin, Rosenfeld & Breitbart, 2002). Even when patients are identified as having anxiety and depression, they are often undertreated (Robinson & Crawford, 2005; Pessin, et al., 2002; Block, 2000).

Patients with advanced disease may be diagnosed with such illnesses as cancer, chronic obstructive pulmonary disease (COPD), heart disease, neurological diseases, kidney failure and dementia but not exclusively. This population of patients is considered to be palliative in nature as their diseases are not considered curable but in many cases they are pursuing some type of life prolonging treatment while they are nearing the end of their life. Terms used throughout this study to describe this patient population's conditions include advanced disease or terminal illness.

Major Depressive Episode, according to the *DSM-IV-TR* (APA, 2000), states that an individual must have five or more of the following symptoms during a two-week period. The symptoms include depressed mood most of the day, significant decrease in pleasure or interest in activities, weight loss or gain, changes in sleep patterns, feelings of restlessness or excessively



slowed movements, increased feelings of fatigue, feelings of worthlessness, diminished concentration, and recurrent thoughts of death or suicide. The *DSM-IV-TR* defines Generalized Anxiety Disorder as having excessive worry for at least six months, difficulty in controlling the worry, restlessness, fatigue, poor concentration, irritability, muscle tension and difficulty sleeping (APA, 2000).

Anxiety and depression are two of the most common psychological issues that arise in the general population and in individuals with advanced disease (Lawrie, et al., 2004; Lloyd-Williams, 2001; Pessin, et al., 2002). Estimates of the development of depression in the general population range from 4%-18% and only 20% of those with Major Depression seek treatment with a mental health provider while 70% of them see a primary care provider (McQuaid, et al., 1999). While patients may tend to turn to their primary care provider, these health providers did not identify 66% of patients with Major Depression (McQuaid, et al., 1999).

Prevalence rates of anxiety and depression in patients with advanced disease vary due to lack of recognized diagnostic criteria in the palliative population as well as professional beliefs as to what is normal sadness versus depression at the end of life (Lawrie, et al., 2004).

Approximately one quarter of all patients admitted to a palliative care unit have depression (Lloyd-Williams, 2001) and even more experience anxiety (Mystakidou, Tsilika, Parpa, Katsouda, Galanos & Vlahos, 2005). Forty-seven percent of cancer patients experience some form of psychiatric disorder at any point of the disease trajectory (Block, 2001). The rates of prevalence of depression in patients who have terminal illnesses vary between 15% and 60% (Lyness, 2007). Women were found to have more incidence of psychological distress overall. Men, single patients and patients with poor performance status had more anxiety while older patients experienced more depression (Mystakidou, et al., 2005). Nearly 80% of psychiatric

disorders that arise in palliative care patients go undiagnosed and untreated (Lawrie, et al., 2004). Performance status described the patient's ability to carry out activities of daily living such as eating, bathing, dressing, ambulating and participating in leisure activities.

Anxiety and depression in patients who have advanced illnesses, such as cancer or chronic obstructive pulmonary disease (COPD), is particularly troublesome as it can intensify pain and other symptoms, hinder recovery, decrease quality of life, increase hospitalizations for symptom control, and increase mortality rates (Robinson & Crawford, 2005; Mystakidou, et al., 2005; Akechi, Okuyama, Sugawara, Nakano, Shima & Uchitomi, 2004). Anxiety and depression can decrease the patient's ability to find meaning and pleasure in their life, and increases risk of suicide (Block, 2001).

There are a number of challenges in meeting the psychological needs of patients who have end stage diseases. Many patients and physicians feel that anxiety and depression are expected when there is a diagnosis of a terminal condition (nihilism) and the symptoms can almost be unnoticed as a result of this belief (Block, 2000; Pessin, et al., 2002). Several studies reported that patients often do not identify themselves as suffering from anxiety and depression (McQuaid, et al., 1999; Block, 2000) or underreport their level of distress (Lloyd-Williams, 2001). Other studies reported that it can be difficult to determine the difference between the symptoms of depression and normal grief reactions experienced by patients with end stage disease (Miller, Adams & Miller, 2006; Pessin, et al., 2002). Patients who are diagnosed with a terminal illness may have a history of a chronic or long standing mental health issue that is complicated by the exacerbation of medical or physical symptoms from the disease. This is then compounded by feelings associated with having a terminal condition such as fears of disability, disfigurement, loss independence and death (Pessin, et al., 2002).

Because anxiety and depression can create significant issues for patients, routine screening is considered paramount in order to initiate the most appropriate treatment as quickly as possible as these patients often have a shorter life expectancy (Mystakidou, et al., 2005). Comprehensive assessment of not only the patient's physical condition, but their psychological distress is imperative in order to improve psychological and physical symptoms thereby improving overall quality of life (Block, 2001). The crisis points that are crucial for reassessment of anxiety and depression in cancer patients include time of initial diagnosis, development of metastasis or disease progression and when entering end of life (Lloyd-Williams & Friedman, 2001). In one study, the symptoms most frequently recognized by primary care providers included low mood, hopelessness, worthlessness and loss of energy (Lawrie, et al, 2004).

Patients with advanced disease are more likely to prefer their primary medical provider to care for their needs versus going to a psychiatrist or mental health provider (Lawrie, et al., 2004). The addition of social workers and behavioral health specialists in the primary care clinic to address psycho-social needs immediately (Rosenthal, 2008) can improve the recognition and implementation of effective treatment for anxiety and depression in the primary care setting, thus decreasing psychological distress for palliative care patients (McQuaid, et al., 1999).

Clinicians are more likely to rely on traditional interventions for anxiety and depression, whether clinically or through medications, even though patients with advance disease may respond more effectively to alternative measures, such as psychostimulants, psychotherapy, meditation and relaxation techniques (Pessin, et al., 2002; Lyness, 2007, Block, 2001). According to one study evaluating physician treatment recommendations, it was found that 35% of the physicians would refer a patient for aromatherapy but only 8% referred for counseling

(Lawrie, et al., 2004). However, it has been reported that both individual and group psychotherapeutic interventions were effective in reducing psychological distress in patients with advanced cancer (Akechi, et al., 2004).

Some argue that clinicians need to become more skilled in assessing, diagnosing and treating anxiety and depression in patients who have terminal illnesses (Pessin, et al., 2002; Lyness, 2007). Additionally, there are structural and economical barriers within the medical profession that limit a provider's ability to assess and treat psychological issues including provider reimbursement incentives and penalties; productivity quotas; and time limitations (Eisenberg, 1992). Researchers have stressed the importance of teaming primary medical care with mental health providers and social workers for coordination of care and facilitation of adequate training for physicians in identifying anxiety and depression in terminal patients (McQuaid, et al., 1999; Rosenthal, 2008; Lawrie, et al., 2004).

The issue of recognizing and treating anxiety and depression in patients with advanced disease has particular relevance to social work in various capacities including medical social work, such as hospice and palliative care services; outpatient behavioral health programs; oncology centers; dialysis clinics; etc. Further research is necessary to explore the relationship between the primary care physician's training in identifying anxiety and depression in patients with end stage diseases and their usage of mental health and social work services.

The purpose of this study is to look at several areas in the primary care setting regarding anxiety and depression in patients who have advanced disease. Areas that will be considered include how primary care providers assess and identify anxiety and depression in patients with advanced disease. This study will also examine what treatment methods primary care providers'

use in treating anxiety and depression in this patient population, including their usage of social work or mental health services.

## **Literature Review**

### **Difficulty in Determining Prevalence of Anxiety and Depression in Palliative Care Patients**

Determining the prevalence of anxiety and depression should be a quick and easy process, however, it is frequently under-recognized in the medical setting and is subject to bias and is affected by factors such as symptom severity, duration and co-morbidities (Hotopf, Chidgey, Addington-Hall, & Lan Ly, 2002). Several studies reported that the prevalence rates for anxiety and depression in the general population range between 4% and 18% (Enguidanos, Davis, & Katz, 2005; McQuaid, et al., 1999; Culpepper, Clayton, Lieberman, & Susman 2008). However, patients who have an advanced illness such as Parkinson's Disease (Kelly, McClement, & Chochinov, 2006), COPD (Gore, Brophy, & Greenstone, 2000) or cancer (Lloyd-Williams, 2001; Block, 2001; McCoubrie & Davies, 2006) are at greater risk for developing psychological distress with prevalence varying between 15% and 60% (Lyness, 2007). Block, (2000), reported that 47% of cancer patients at various stages of disease meet the diagnostic criteria for psychiatric disorders. According to a study by Hill, Geist, Goldstein, & Lacasse, (2008), prevalence rates for anxious feelings in patients with COPD ranged from 2% to 96%. Rates ranged from 10% to 33% for generalized anxiety disorders and rates varied between 8% and 67% for panic disorders (Hill, et al., 2008).

While depression is one of the most commonly experienced mental health illnesses, it is often the easiest overlooked (Hotopf, et al., 2002). Lawrie, et al., (2004) reported that roughly 80% of patients with cancer have unrecognized and untreated psychological distress. Researchers indicated that while having a terminal illness increases the risk of developing

anxiety and depression, it is not inevitable nor is it a normal and expected part of the dying process (Periyakoil & Hallenbeck, 2002; Lyness, 2007).

There are a number of factors that play a role in the lack of recognition and under-treatment of anxiety and depression in the palliative care population. The factors are in part physician related (Lawrie, et al., 2004), patient related (Lloyd-Williams, 2001) and disease related (Reeve, Lloyd-Williams, & Dowrick, 2008).

There are several physician related factors that contribute to the failure to recognize and treat anxiety and depression in patients with terminal illnesses. Physician bias plays a role due to the stigma that is associated with mental health disorders (Lawrie, et al., 2004; Block, 2000). Many physicians do not have adequate skills or training to identify psychological distress, especially in the context of complex, terminal diseases (Block, 2000). Clinician time constraints affect their ability to explore issues of anxiety or depression (Block, 2000).

Physicians may fear that examining emotional concerns may increase the patient's feelings of distress (Block, 2000). Additionally, physicians may be reluctant to bring up issues of anxiety and depression, especially in relation to advanced disease, due to their own emotional responses (transference phenomenon) (Block, 2000). Transference phenomenon happens when an individual unconsciously transfers feelings or reactions from their past onto the present (Hughes & Kerr, 2000). Transference and countertransference, while commonly addressed in social work is not readily acknowledged or understood by medical providers and can positively or negatively define and impact the physician-patient relationship (Zinn, 1990; Hughes & Kerr, 2000).

Furthermore, it has been noted that many physicians intend on treating anxiety and depression if they screen for it (Robinson & Crawford, 2005), therefore, many physicians are

hesitant to initiate treatment in patients who are terminal due to their short life expectancy so do not look for these psychological issues (Block, 2000). Another major factor affecting the health care providers' ability to adequately assess for anxiety and depression is the lack of standardized diagnostic criteria in this population of patients (Eisenberg, 1992; Payne, et al., 2007; Roundy, et al., 2005).

Moreover, there are a number of patient related factors that affect assessment and treatment for psychological distress. Patient non-disclosure contributes to the low rates of diagnosing anxiety and depression (Lawrie, et al., 2004; Lloyd-Williams, 2001). Patients will often avoid expressing concerns about their emotions due to fear of being diagnosed with a mental illness and the associated stigma (Block, 2000). Patients may not recognize that they are experiencing anxiety and depression, attributing the symptoms to their medical disease or medication and treatment side effects (Hotopf, et al., 2002). Patients, like physicians, may believe that depression and anxiety are a normal and expected part of the dying process (Block, 2000).

A central factor that challenges the physician in determining anxiety and depression in patients with advanced illnesses is the fact that many of the symptoms of depressed or anxious mood might be the normal and expected symptoms manifested from the underlying disease (Hotopf, et al., 2002). It can be difficult to identify anxiety and depression in this population include the issue of somatic complaints, such as fatigue, appetite changes and sleep disturbances (Reeve, et al., 2008; Lawrie, et al., 2004). Also, there is an expectation that patients who have advanced and progressive medical illnesses would have periods in which they are sad or expressing feelings of "depression". The question becomes, "When does this expected and

reasonable form of depressed mood become a significant mental illness?" (Hotopf, et al., 2002; Block, 2000).

Likewise, determining anxiety and depression can be particularly difficult in patients who have COPD as there are significant similarities between the symptoms of the physical disease and those of anxiety (Hill, et al., 2008). Taking this into consideration, it has been reported that patients who have COPD have higher levels of anxiety than compared to patients with cancer or heart diseases (Hill, et al., 2008). It should also be noted that COPD patients with anxiety have been found to have higher rates of depression which may account for 66% of the measurement variances between anxiety and depression prevalence rates in this population (Hill, et al., 2008). Estimates for the prevalence of COPD vary depending on the criteria used for diagnosis (Halbert, Isonaka, George & Iqbal, 2003). However, it has been determined that approximately 15% of all smokers may develop COPD in their lifetime, additionally, individuals who use wood for heating and cooking may have three to four times the risk of developing COPD (Halbert, et al., 2003). Furthermore, most studies have determined the prevalence rate of COPD to be 4 to 10% of all adults world-wide (Halbert, et al., 2003). Due to the high prevalence rates of COPD, it is very imperative for providers to better address psychological distress within this palliative population.

Furthermore, there are a number of other factors that play a role in the significant disparity in the prevalence rates for anxiety and depression in patients with advanced disease. The wide variation in rates can be attributed, in part, to how researchers and clinicians define the terms of anxiety and depression (Hill, et al., 2008). Hotopf, et al., (2002) indicated that a diagnosis of depression is usually restricted to patients with Major Depressive Disorder by psychiatrists; however, in the psychiatric classification for Mood Disorders, the symptom lists and thresholds of the symptoms are arbitrary to the clinician completing the assessment. When



reviewing the *DSM-IV-TR* it is vital to have an understanding of the various criteria for determining anxiety and depressive disorders as there is overlap between the different mood and anxiety disorders but more importantly, researchers may blend and merge some of these categories in the process of their study while others may staunchly keep them separate (Hotopf, et al., 2002). Therefore, when researching prevalence rates, it is important to have an understanding of what diagnostic criteria the researcher is utilizing as it may have significant effects on estimating the rate of prevalence (Zeiss, Lewinsohn, Rhode & Seeley, 1996).

In addition, the type of methods used in studies (Hill, et al., 2008) will impact interpretation of the results. Zeiss, et al, (1996), recommended that diagnostic criteria should be used on a standardized basis to measure prevalence of psychological distressing symptoms instead of self-reporting or diagnoses that are based on clinical judgment due to higher rates of subjective biases.

Finally, variability in prevalence rates may be explained by the heterogeneity of the population sample (Reeve, et al., 2008) and sample size (Hill, et al., 2008). Differences in assessment instruments and cutoff points for various thresholds and indexes that are used to identify the presence of anxious and depressive symptoms may also contribute to the wide ranges in prevalence rates of anxiety and depression in patients with advanced illnesses (Hill, et al., 2008). Furthermore, the timing of the assessment for depression may also affect prevalence rates (Lloyd-Williams & Freidman, 2001; Reeve, et al., 2008). Lloyd-Williams and Friedman (2001) reported that the patient's in their study lived a mean survival time of 32.2 days, indicating that the majority of patients assessed were in the last few weeks of their life, and that 22 percent of them had depression.

## **Risk Factors for Developing Anxiety and Depression at End of Life**

There are a number of risk factors that patients with advanced disease have that do not apply to the general population. Patients who are in the terminal phases of their disease process are more susceptible to the development of anxiety and depression as well as other psychological disorders (Payne, et al., 2007). These risk factors, if present, should raise concerns about the possibility of psychological distress. These symptoms may include changes in functional abilities (such as vision or hearing) (Zeiss, et al., 1996; McQuaid, et al., 1999); physical activity limitations (such as shopping, performing hobbies) (Zeiss, et al., 1996; Block, 2000); decreased ability to perform activities of daily living (such as bathing, dressing and toileting) (Tsunoda, Nakao, Hiratsuka, Yasuda, Shibusawa, & Kusano, 2005; Zeiss, et al., 1996) and the presence of pain and other uncontrolled symptoms (Zeiss, et al., 1996; Block, 2000).

Other factors that increase the risk for developing anxiety and depression in patients with advanced disease include severe fatigue (Akechi, et al., 2004; Tsunoda, et al., 2005), and the loss of independence (Akechi, et al., 2004, Zeiss, et al., 1996; Lloyd-Williams & Friedman, 2001). Zeiss, et al., (1996) indicated that only 21% of patients who have high levels of functional impairment became depressed compared to 11% of those who had no impairments. However, Reeve, et al (2008) reported that 77% of patients with poor functional abilities had depression compared to a prevalence rate of 23% for patients with good functional status.

Furthermore, increased social isolation may be related to increased rates of anxiety and depression (Zeiss, et al., 1996; Reeve, et al., 2008; Akechi, et al., 2004). Isolation may happen as a result of disease or treatment burdens (Lloyd-Williams & Friedman, 2001) or changes in key support relationships (Lloyd-Williams & Friedman, 2001; Hill, et al., 2008).

In addition, patients who have severe pain and other physical symptom burdens (Tsunoda, et al., 2005; Block, 2000) are at risk for developing anxiety or depression. Zeiss, et al., (1996) stated that pain and illness contribute to decreased functional abilities which lead to depression. Mystakidou, et al., (2005) stated that patients with severe pain were more likely to develop depression while patients with decreased functional status were more likely to develop anxiety. Also, disfigurement from the disease or treatment side effects may be another potential risk factor for creating psychological distress (Lloyd-Williams & Friedman, 2001; Chen & Chang, 2004).

Patients who have been given a diagnosis of cancer are at risk for developing anxiety and depression. A diagnosis of cancer has several points in the disease trajectory that may place a person in psychological crisis. These critical times are the time of initial diagnosis, disease progression or spread (metastasis) and the terminal phase (Lloyd-Williams & Friedman, 2001; Hoffman & Weiner, 2007). According to Mystakidou, et al., (2005), female cancer patients had more psychological distress overall than male patients. Single patients, patients who were in active cancer treatment such as chemotherapy or radiation and patients with low performance status were at a higher risk of developing anxiety. They also reported that older cancer patients were more likely to develop depression than younger patients. Active treatment may cause uncontrollable symptoms such as nausea and vomiting resulting in decreased physical and emotional well-being (Hoffman & Weiner, 2007).

Another incurable and debilitating illness that has a strong connection to the development of anxiety and depression is COPD. For patients who have COPD, there is a close relationship between the patient's level of dyspnea (shortness of breath) and the prevalence of anxiety (Hill, et al., 2008). In a study Gore, et al., (2000), the HADS (Hospital Anxiety and Depression Scale)

identified 90% of COPD patients with anxiety and depression compared to only 52% of patients with non-small cell lung cancer. Patients whose COPD was caused by their smoking have higher levels of pre-disease anxiety and depressive symptoms (Hill, et al., 2008). The levels of anxiety and depressive symptoms were found to be directly correlated to the level of dyspnea a patient experiences (Hill, et al., 2008). It was found that COPD patients had significantly worse physical disease and functional performance status than lung cancer patients resulting in higher levels of anxiety and depression as well (Gore, et al., 2000; Fitzsimons, et al., 2007). Patients with COPD have specific factors that may contribute to the development of anxiety and depression that are not seen to the same degree in other disease processes. Strong emotions such as anger or frustration may contribute as triggers for developing anxiety in COPD patients (Hill, et al., 2008).

Together with the above stated factors, a patient's psychiatric history can increase exacerbation of psychological symptoms in patients who have terminal illnesses (Hill, et al., 2008; Akechi, et al., 2004; Lloyd-Williams & Friedman, 2001). In addition, fear of disease recurrence (Hoffman & Weiner, 2007), such as cancer, and approaching death (Lloyd-Williams & Friedman, 2001) can contribute to a patient's psychological distress.

Several studies examined additional possible risk factors for developing psychological distress and identified higher prevalence rates of anxiety and depression in patients who are younger than 50 years old (Akechi, et al., 2004; Lloyd-Williams & Friedman, 2001). Females, similar to the general population (Reeve, et al., 2008), were also found to be more at risk of developing psychological distress (Hill, et al., 2008; Akechi, et al., 2004; Mystakidou, et al., 2005). Lloyd-Williams and Friedman (2001) reported that 42% of patients with breast cancer, all females, had depression. Reeve, et al., (2008), however, stated that the association between

gender and rates of depression in palliative care patients remain uncertain. Furthermore, financial stressors (Lloyd-Williams & Friedman, 2001; Hoffman & Weiner, 2007; Akechi, et al., 2004) were also reported to be a contributing factor in the development of psychological distress.

There has been much research on the effects of disease burden on cancer patients regarding anxiety and depression, but there has not been as much for other disease processes. Researchers reported that patients with COPD have a higher rate of anxiety and depression compared to cancer patients as well as poorer overall quality of life (Fitzsimons, et al., 2007; Hill, et al., 2008). Patients with end stage renal disease and heart failure are also at high risk of developing anxiety and depression due to poor quality of life factors (Fitzsimons, et al., 2007). Geriatric patients with cancer and other advanced illnesses are also at high risk for developing significant depression (Nelson, Cho, Berk, Holland & Roth, 2010).

Having a terminal diagnosis or multiple medical problems, in and of itself does not put patients at a high risk of developing anxiety and depression. However, having untreated pain and other intractable symptoms and a poor performance status (Payne, et al., 2007; Zeiss, et al., 1996; Mystakidou, et al., 2005) as well as increased social isolation (Fitzsimons, et al., 2007) made patients more vulnerable to these psychological disorders. Some diseases, such as COPD, result in higher levels of anxiety and depression (Fitzsimons, et al., 2007). Patients who have poor overall quality of life are also at higher risks for developing psychological distress (Fitzsimons, et al., 2007). Significant psychological distress also increases a patient's risk of suicide and requests for a hastened death (Block, 2000; Akechi, et al., 2004).

### **Challenges in Diagnosing Anxiety and Depression Using DSM-IV-TR Criteria**

It is difficult to determine whether psychological symptoms are caused by depression or the medical disease (Lyness, 2007; Miller, et al., 2006; Hill, et al., 2008). A number of studies

highlighted the challenges in diagnosing anxiety and depression in patients with terminal medical conditions based on the *DSM- IV- TR* criteria and the somatic symptoms often experienced such as fatigue, weight loss, sleep disturbances and concentration difficulties (Lawrie, et al., 2004; Lloyd-Williams & Friedman, 2001; Miller, et al., 2006). Several studies discussed the difficulty in screening for depression because of the reliance on somatic complaints, especially fatigue and anhedonia (loss of interest or pleasure in activities) (Robinson & Crawford, 2005; Pessin, et al., 2002; Wasteson, et al., 2009). In addition, anxiety can mimic physical illness in patients with respiratory distress such as COPD or lung cancer by increasing shortness of breath and cardiovascular symptoms (Kelly, et al., 2006). Fatigue, weight loss and insomnia are hallmark symptoms experienced by cancer patients (Lawrie, et al., 2004; Hoffman & Weiner, 2007).

Kelly, et al., (2006) stated that screening instrument designers have a particular view of depression that influences the cognitive, behavior and somatic domains that are evaluated. There is a lack of universally accepted diagnostic criteria for anxiety and depression in patients who are terminally ill (Lawrie, et al., 2004). Fatigue, anhedonia and depressed affect have been identified as hallmark symptoms of depression in the International Classification of Diseases (ICD) (Robinson & Crawford, 2005). Relying solely on these somatic complaints does not truly reflect symptoms of anxiety and depression for patients who have advanced disease as these issues are often a result of the terminal disease and medication or treatment side effects (Lawrie, et al., 2004; Wasteson, et al., 2009).

Currently there are two frameworks to determine anxiety and depression, the ICD-10 and the DSM-IV-TR (Reeve, et al., 2008; Robinson & Crawford, 2005). Reeve, et al., (2008) raised concerns between how these two prominent methods define anxiety and depression and identified the issue that there is only an 83% similarity found between the two. Researchers have

recommended the *DSM-IV-TR* as the preferred diagnostic criteria (Hoffman & Weiner, 2007); although there is a lack of consensus on the role somatic symptoms play in the diagnostic process (Lawrie, et al., 2004; Pessin, et al., 2002; Reeve, et al., 2008). The primary features of depression, according to the *DSM-IV-TR*, such as fatigue, weight loss and insomnia do not apply to terminally ill patients (Block, 2000; Lawrie, et al., 2004) due to attribution of these same symptoms in relation to the terminal disease (Lloyd-Williams, 2001; Reeve, et al., 2008). Other research has recommended modifications to the DSM criteria for persons who have advanced disease (Kelly, et al., 2006; Reeve, et al., 2008).

### **Professional Barriers to Identification and Treatment of Anxiety and Depression**

Evidence suggests that a significant number of patients in the primary care setting experience mental health problems, however management of these psychosocial issues are often neglected (Lesser, 2000; Lawrie, et al., 2004). Several barriers to appropriate assessment and treatment of anxiety and depression in the primary care setting have been acknowledged, including time constraints (Lesser, 2000; Vodermaier, Linden, & Sui, 2009; Hill, et al., 2008), insufficient education regarding identification and treatment of psychiatric illnesses (Hoffman & Weiner, 2007; Block, 2000; McQuaid, et al., 1999), concerns about stigmatizing the patient with a mental health diagnosis (Hoffman & Weiner, 2007; Pessin, et al., 2002), and therapeutic nihilism (the belief that psychological distress is to be expected and a normal experience for a person who is dying) (Block, 2000).

According to Eisenberg (1992), clinicians and patients have a “covert” arrangement that only physical symptoms are legitimate issues to address during the 6-7 minute clinic visit. Addressing mental health issues can take considerable amounts of time to manage symptoms and provide support which creates barriers to effective patient care (Lesser, 2000; Eisenberg, 1992).

Other researchers discussed the paternalistic approach that physicians take with patients (Zilberfein & Hurwitz, 2003), doubting the legitimacy of psychiatric diagnoses due to the lack of objective diagnostic testing through labs or other procedures (Eisenberg, 1992). Research has indicated that physicians fear that exploring feelings of anxiety and depression may cause the patient further emotional distress (Block, 2000) or result in anger, leading the patient to seek medical treatment elsewhere (Eisenberg, 1992).

Additionally, the transference phenomenon also affects the dynamics of the patient-physician relationship (Zinn, 1990). Both the patient and physician bring their own needs and desires to the patient-physician relationship as well as their past experiences, biases and emotional needs (Zinn, 1990; Hughes & Kerr, 2000). Transference plays a key role in the medical encounter because imbalance of the patient-physician relationship. The patient needs the physician more than the physician needs the patient (Zinn, 1990). Also, physicians have their own motivation and agenda in the medical encounter that affects their ability to address the patient's needs (Hughes & Kerr, 2000).

Several studies stated that physicians are uncomfortable with assessing the symptoms of anxiety and depression (Hill, et al., 2008) and have difficulty determining the difference between grief or sadness and symptoms of depression (Durkin, Kearney, & O'Siorain, 2003; Pessin, et al., 2002). Reliance on Kubler-Ross's stages of grief theories taught in medical school has resulted in many physicians believing that grief is expected for all patients who are dying, resulting in poor recognition of psychological distress (Durkin, et al., 2003). Therapeutic nihilism happens when physicians experience a sense of hopelessness in caring for their dying patients (Block, 2000) and medication is considered pointless and not initiated due to the patient's short life expectancy (Lloyd-Williams, 2003; Pessin, et al., 2002).



Additionally, there are structural and economical barriers within the medical profession that limit a provider's ability to assess and treat psychological issues. These include the way that providers are paid by insurance companies. A clinician who is conscientious in providing clinical care for psychological distress is penalized by the third party payers (Eisenberg, 1992). The structure of the current health care system pressures the clinician to be productive in the number of patients that are seen in a day as well as how they are reimbursed for services provided (Eisenberg, 1992). With an average office visit ranging between 6 to 15 minutes, there is not enough time to explore psychological concerns, especially if the clinician is expected to the quota for number of patients seen (Eisenberg, 1992). Physicians are not given incentives, including financial, to provide counseling to patients, although, it has been acknowledged that management of psychological issues may lead to other offsets by reducing inappropriate medical and hospital care (Eisenberg, 1992).

### **Patient Non-Disclosure**

Several studies reported on the reasons that patients do not accurately report their psychological distressing symptoms. Covert factors may include fear they are wasting their physician's time or in some way to blame for their distress (Lloyd-Williams, 2001). Patients may fear that nothing can be done so they don't bring these issues to their physician's attention (Durkin, et al., 2003) because they believe their feelings are a normal and expected reaction to their terminal status (Block, 2000; Pessin, et al., 2002). Patients may not want to "bother" their physicians with symptoms that they believe may be insignificant or that will "distract" their physician from perceived more important duties (Pessin, et al., 2002). According to Eisenberg (1992), medical practices do not lend themselves to meeting the patient where they are at. Instead, patients, as well as physicians, are groomed to believe that the only legitimate issues that

should be raised in the clinical exam are those that are directly related to the physical disease: when patients present themselves and are ready to talk about their emotional concerns, they are often shut down by the provider (Eisenberg, 1992).

Furthermore, it was found that patients often do not recognize their symptoms of depression or anxiety as a medical problem (Enguidanos, et al., 2005) and underestimate the level of their own distress (Lloyd-Williams, 2003; Hoffman & Weiner, 2007). According to Lloyd-Williams (2001) people have only their own past experiences by which to judge their reactions. Hotopf, et al., (2002) performed a systematic literature review regarding prevalence of depression and found that depression rates are higher when patients are asked about depressive symptoms versus raising concerns on their own. This example supports the issue that patients are less likely to bring concerns of depression to their providers' attention.

Other factors that contribute to patient non-disclosure include the issue that some patients may be reluctant to share their symptoms due to embarrassment (Hoffman & Weiner, 2007). Fear of the stigma associated with a psychiatric diagnosis may deter both patients and physicians from exploring issues of psychological distress (Block, 2000; Eisenberg, 1992; Pessin, et al., 2002). In addition, patients who may have been ready to discuss their emotional distress with their primary care provider hesitate only to find themselves being cut off by the physician who chooses to focus on physical symptoms rather than the psychosocial aspects of their distress (Eisenberg, 1992).

Furthermore, many patients, along with physicians, believe that emotional distress is expected for patient who have advanced or terminal illnesses making it difficult to differentiate normal emotional expressions from the more complex psychiatric disorders (Pessin, et al., 2002). Concluding that patients are reluctant are less likely to self-disclose feelings of anxiety and

depression, or any other mental illness for fear of distracting their physician from managing the disease and physical symptoms. Also patients may be reluctant to raise these concerns for fear that they are “going crazy” and fear the associated stigma (Durkin, et al., 2003; Block, 2000). Because patients do not readily volunteer these issues, it is imperative for the health care team to take the time to evaluate for signs of anxiety and depression at routine appointments throughout the disease trajectory (Durkin, et al., 2003; Enguidanos, et al., 2005).

### **Burdens of Untreated Anxiety and Depression**

The literature has repeatedly indicated that psychological distress such as depression and anxiety in patients who have terminal illnesses are often unrecognized and undertreated. This has resulted in significant burdens to the patient including decreased ability to experience pleasure (Pessin, et al., 2002; Block, 2000); increased functional impairments (Hotopf, et al., 2002); increased disease burden (Payne, et al., 2007); decreased social interaction (McCoubrie & Davies, 2006); and decreased quality of life (Pessin, et al., 2002; Hotopf, et al., 2002; Robinson & Crawford, 2005). Significant depression and anxiety affects the patient’s capacity to make treatment decisions (Mystakidou, et al., 2005) and reduces their ability to have closure and do the emotional work of dying (Block, 2000). Untreated symptoms can lead to the patient’s request for hastened death or suicide ideation (Pessin, et al., 2008; Robinson & Crawford, 2005; Block, 2000).

In addition to the burdens that patients experience, physicians also find challenges. Untreated depression and anxiety in patients who have advanced disease can affect the patient’s compliance with medical treatment and therapies (McCoubrie & Davies, 2006; Robinson & Crawford, 2005); create difficulty in managing pain and other symptoms (Block, 2000; McCoubrie & Davies, 2006); increase length of stay and hospitalizations (Kelly, et al., 2006);

and ultimately limit the primary care physician's ability to provide effective care (Payne, et al., 2007). Furthermore, physicians are often penalized for spending the time needed to assess and counsel patients with psychological distress (Eisenberg, 1992). Given the significant effects of psychological distress on patients, proper identification and initiating treatment in a timely fashion is very important (Kelly, et al., 2006).

### **Screening for Anxiety and Depression in Primary Care**

Initial screening and repeated assessments of palliative care patients' mood is important throughout the disease trajectory to determine when medication or psychological intervention may be needed (Mystakidou, et al., 2005; Hill, et al., 2008; Culpepper, et al., 2008). The patient may have strong coping skills to deal with certain parts of the illness better than others (Hoffman & Weiner, 2007; Hill, et al., 2008). The ability to cope and adapt to disease changes varies according to the patient's age, life experiences, social support, attitudes and cultural values (Germain & Gitterman, 1980).

Many studies have been done on various screening tools with mixed results but the common finding was that physicians who work with the terminally ill need to inquire about the patient's emotional status in addition to their physical status through the diagnostic clinical assessment (Pessin, et al., 2002; Durkin, et al., 2003; Payne, et al. 2007). It was reported that 73% of the physicians stated they routinely assessed for depression and 69% of the physicians reported they never used a screening tool (Lawrie, et al., 2004).

Most of the screening instruments to evaluate anxiety and depression were developed and validated on physically healthy patients and not on patients who are dying (Lloyd-Williams, 2001). Of the various screening methods often studied, the Hospital Anxiety and Depression Scale (HADS) (McCoubrie & Davies, 2006; Miller, et al., 2006; Tsunoda, et al., 2005) and the

Beck Depression Inventory-Short Form (BDI-SF) were found to be best designed to deal with the influences of somatic symptoms (Pessin, et al., 2002). The Center for Epidemiologic Studies-Depression Scale (CES-D) was found to be the most appropriate for geriatric cancer patients (Nelson, et al., 2010). One common problem with self reporting forms is that depression is often over diagnosed in patients who are medically ill because the cut off scores were based on physically healthy individuals and does not equally compare to patients with advanced disease (Pessin, et al., 2002; Payne, et al., 2007). Another factor that confounds the validation of depression in this population is the issue of hopelessness and how it is interpreted by the patient, family and health care provider (Nelson, et al., 2010).

Many of the current screening tools are too long or complicated for patients with advanced medical conditions (Robinson & Crawford, 2005; Kelly, et al., 2006) or lack specificity because the questions address somatic and functional criteria that can generate false positives in the terminally ill population (Periyakoil & Hallenbeck, 2002; Nelson, et al., 2010). Many of the instruments available did not allow for the duration of symptoms or their impact on the patient's functional status and medical disease impairments (Wasteson, et al., 2009). It was widely reported among the research that the current standardized screening tools do not meet the unique needs of the palliative care patient population and that adjustments need to be made to create a tool that is specifically designed to assess anxiety and depression in patients with advanced disease (Nelson, et al., 2010).

Using a two question screening tool has been recommended as the best option to explore a patient's mood to determine whether a more formal clinical interview is warranted (Periyakoil & Hallenbeck, 2002). Questions may include "Are you depressed?" or "Do you feel depressed most of the time?" and "Do you feel you are better off than many of other people in similar

situations?” or “Have you lost interest in activities or things that you would normally enjoy?” (Periyakoil & Hallenbeck, 2002; Payne, et al., 2007; Hoffman & Weiner, 2007). If the patient responds yes to either or both of these types of questions the screen is considered positive, warranting further clinical assessment (Payne, et al., 2007; Hoffman & Weiner, 2007; Block, 2000). Using the two question screening tool has a high sensitivity and low false negative rates making it an appropriate tool for palliative care patients (Payne, et al., 2007; Breitbart, et al., 2009) and help to determine whether a more detailed assessment for anxiety and depression is necessary.

### **Physician Best Practices**

Several studies addressed current best practices that can guide primary care providers in addressing psychological distress in their patients who have advanced disease. Physicians who care for patients with advanced disease need to be aware of the unique risk factors for developing anxiety and depression that this population of patients may experience (Hoffman & Wiener, 2007; Hill, et al., 2008; Block, 2000). It is recommended that all patients with cancer, chronic illnesses and other palliative care patients should be screened for depression (Robinson & Crawford, 2005). Psychological well being for patients with terminal illness is vital for maintaining good quality of life; therefore, addressing psychological distress is a crucial part medical care (Tsunodo, et al., 2005). Early identification (Culpepper, et al., 2008) and frequent reassessment (Hoffman & Weiner, 2007; Block, 2001; Wasteson, et al., 2009) of psychological distress as well as implementation of appropriate treatment interventions is necessary for reducing symptoms and improving overall quality of life (Durkin, et al., 2003). Frequent reassessment is encouraged as the patient’s emotional well-being will fluctuate throughout the disease process (Block, 2001). Also, according to Hill, et al., (2008), depression and anxiety

within the context of chronic illnesses will follow different patterns and will vary from one disease to another.

It is essential for physicians to be aware of the risk factors that palliative patients may experience in order to implement the appropriate treatment as quickly as possible (Culpepper, et al., 2008). Paying attention to pain and other symptoms is of particular importance due to the significant impact physical symptoms has on emotional well-being (Block, 2001; Culpepper, et al., 2008; McCoubrie & Davies, 2006). According to Block (2000), pain is an issue for 60% to 90% of cancer patients during the last year of their life. Patients with COPD are particularly susceptible to experiencing psychological distress (Hill, et al., 2008). In addition to pain and other physical symptoms, physicians should also be aware of the role that functional impairment plays with the development of anxiety and depression (Zeiss, et al., 1996).

Distinguishing a depressive disorder from depressive symptoms attributed to the medical disease (Hill, et al., 2008) is important in order to determine the most appropriate therapeutic intervention. A thorough medical examination is recommended to rule out the possibility of possible organic conditions such as metastatic cancer or other syndromes that may mimic symptoms of depression (Block, 2000). Also, physicians are encouraged to consider the patient's expressions of emotions in relation to what is expected at the various stages of disease trajectory and if the patient's subjective experience is disproportionate to the medical findings, depression should be suspected (Hoffman & Weiner, 2007).

Death anxiety is another factor that should be explored in patients with advanced disease (Periyakoil & Hallenbeck, 2002). A comprehensive assessment of psychosocial and spiritual issues is important to identify the patient's strengths and fears (Block, 2001). The physician is encouraged to inquire about the patient's concerns about death or the dying process and any fears

the patient may have about the course of the medical disease (Block, 2000). Inquiring about these concerns assists with the assessment of the patient's coping styles (Zilberfein & Hurwitz, 2003).

Physicians are encouraged to employ routine screening tools for identifying anxiety and depression (Robinson & Crawford, 2005; Wasteson, et al., 2009). Due to the complexities of differentiating psychological disorders within the context of chronic medical disease, it has been recommended that physicians use simple screening questions to identify those patients with anxiety and depressive symptoms that may benefit from a more detailed evaluation (Hill, et al., 2008). Early diagnosis and implementing the appropriate treatment quickly may influence the patient's overall quality of life and physical illness (Durkin, et al., 2003). Furthermore, the physician should treat the psychiatric and physical illnesses simultaneously as each influence the other (Culpepper, et al., 2008).

Once anxiety and depression have been identified, it is imperative to initiate treatment as soon as possible (Hill, et al., 2008). Culpepper, et al., (2008) stated that there are four steps for treating anxiety and depression. These steps include using a formal diagnostic or screening tool; screening all patients who present with symptoms of psychological distress, substance abuse and suicide ideation; treat with the intention of obtaining remission through the use of medication and/or therapy; and follow up with the appropriate maintenance therapy.

A combination of interventions has been found to be beneficial in treating anxiety and depression in patients with advance disease. Providing pharmacology (antidepressants and anti-anxiety medications), psychotherapy and patient education are the most effective treatment strategies (Lloyd-Williams, 2001; Durkin, et al., 2003; Periyakoil & Hallenbeck, 2002).

Eisenberg (1992) stated that primary care physicians do not need to specialize in these treatments



but do need to recognize the symptoms and refer the patients to the appropriate specialists. Physicians are encouraged to develop good working relationships with mental health professionals (Hoffman & Weiner, 2007). Sometimes the supportive therapy alone can be adequate treatment for depression and anxiety. This support can be provided by social workers, or other mental health professionals (Block, 2000).

Furthermore, research stated that physicians who care for patients with advanced disease need to be competent in providing supportive care for psychological distress (Block, 2000). Communication skills (Hoffman & Weiner, 2007), in the form of active listening, exploring concerns, emphasizing the patients' strengths and facilitating family interviews (Block, 2000) are important skills. Providing education and reassurance to the patient and their family are also key elements in the treatment of anxiety and depression in palliative care (Block, 2001).

### **Effects of Different Treatment Options on Anxiety and Depression of Patients at End of Life**

It has been reported that once depression or anxiety have been identified, treatment should be initiated immediately because it can improve quality of life, decrease distress and possibly increase life expectancy (Miller, et al., 2006; Block, 2000). There are several standard methods of managing palliative care patients who have depression and anxiety. They include providing good support, relief of poorly controlled physical symptoms (Lloyd-Williams, 2001; Mystakidou, et al., 2005), psychotherapy, education, and medications (Periyakoil & Hallenbeck, 2002, Culpepper, et al., 2008). It has been recommended that the primary care physician treat the medical illness and the psychological distress at the same time, as each influences the other (Culpepper, et al., 2008).

The use of pharmacological interventions for management of depression and anxiety in patients who have advanced disease requires special attention due to complexities of medication side effects (Periyakoil & Hallenbeck, 2002; Miller, et al., 2006). Medications need to be determined on an individual basis while keeping in mind the patient's overall prognosis, side effects to avoid and side effects that might enhance the patient's quality of life (Periyakoil & Hallenbeck, 2002; Hill, et al., 2008; Lyness, 2007).

Several classes of medications are often considered for the treatment of depression including selective serotonin reuptake inhibitors (SSRI's); serotonin norepinephrine reuptake inhibitors (SNRI's); tricyclic antidepressants; and psychostimulants (Block, 2000; Miller, et al., 2006). SSRI's are the drug of choice for treatment of depression in patients with advanced disease because they have a relatively quick response time and fewer side effects than the tricyclic antidepressants (Periyakoil & Hallenbeck, 2002; Lloyd-Williams, 2003; Hotopf, et al., 2002). Tricyclic antidepressants can be helpful in patients who have neuropathic pain issues (Lloyd-Williams, 2003). Psychostimulants are particularly helpful when a patient's life expectancy is weeks to months and provide positive side effects such as increased appetite and energy and acts against the sedative opioid effects of pain management (Periyakoil & Hallenbeck, 2002; Block, 2000; Miller, et al., 2006). Clinicians are more likely to prescribe antianxiety medication for patients who are medically ill even if they may not have an anxiety disorder (Pessin, et al., 2002).

Psychotherapy and relaxation techniques have been found to be helpful in palliative care patients and these interventions avoid side effects and potential drug interactions (Pessin, et al., 2002, Hill, et al., 2008). A combination of breathing exercises, progressive muscle relaxation

and comprehensive patient education has been found to decrease anxiety levels in COPD patients (Hill, et al., 2008).

Despite the research on the benefits of psychotherapy, very few physicians actually access this type of support. In a study by Lawrie, et al., (2004), in a study of 134 hospice and palliative care physicians in the United Kingdom, 35% of the physicians reported that they would refer a patient for aroma therapy but only 8% indicated they would refer for counseling. Even patients who are at the end of their life may benefit from treatment for anxiety and depression (Lawrie, et al., 2004) Research supports the role of psychotherapy in management of depression in palliative care patients; however, antidepressants are often the treatment of choice due to their quick onset of action (Lawrie, et al., 2004). Medication therapy has been found to relieve symptoms of depression and psychological distress in 80% of palliative care patients (Block, 2000); however, it takes approximately three weeks for any antidepressant to work on the depressive symptoms (Lloyd-Williams, 2003).

Psychotherapeutic interventions such as individual and group counseling, (Akechi, et al., 2004), cognitive behavioral therapy (Zeiss, et al., 1996) and supportive therapy (Block, 2000) can be particularly helpful in patients with advanced disease. Psychotherapy can help a patient with life review, setting priorities and meaningful goals, problem solving and dealing with dysfunctional thinking patterns (Lyness, 2007; Culpepper, et al., 2008). Exploring fears of death and dying and assessing spiritual and religious assets can increase the patient's coping abilities (Block, 2000) and decrease symptoms of anxiety and depression. Cognitive behavioral therapy and supportive therapy can be beneficial to patients with anxiety and depression who have the cognitive capabilities, motivation and a longer life expectancy (Lyness, 2007; Lloyd-Williams, 2003; Zeiss, et al., 1996).

Furthermore, research has indicated that adjuvant psychotherapy in patients with cancer has been beneficial to help create a “fighting spirit”, address negative thinking patterns and behaviors, allow for expression of feelings (Lloyd-Williams, 2003) and to find meaning and purpose while facing a terminal illness (McCoubrie & Davies, 2006). Additionally, by providing the patient with self-help strategies, they develop a sense of independence and an element of control that may enhance overall improved well being (Sloman, 2002; Post & Collins, 1981). Germain and Gitterman (1980) stress the use of professional social workers in this work because of their knowledge, translation of values in practice and professional competence.

### **The Influence of the Traditional Medical Model**

The traditional medical model of care is a hierarchal structure in which the physician uses a curing versus caring approach to patient care (Zimmerman & Dabelko, 2007; Zilberfein & Hurwitz, 2003). Physician training stresses autonomy with little emphasis on a collaborative approach (Kitchen & Brook, 2005). This model of care can be very difficult for patients and families to navigate and the physician takes a more active role in course of care decisions than the patient (Zimmerman & Dabelko, 2007; Zilberfein & Hurwitz, 2003; Enguidanos, et al., 2005). The traditional model does not usually consider the role of emotional, spiritual and psychosocial influences on the individual with advanced disease (Zimmerman & Dabelko, 2007; Durkin, et al., 2003; Zilberfein & Hurwitz, 2003). Traditionally, referrals for mental health services are usually self-initiated or based on the judgment of the physician. Due to the issues of patient non-disclosure and physician biases, among others, many patients who might benefit from supportive therapy are not connected to mental health services (Vodermaier, et al., 2009).

Furthermore, many social work positions are also steeped in the traditional medical model of care such as discharge planning where the primary focus is on the immediate needs

once the patient is discharged from the hospital (Zilberfein & Hurwitz, 2003; Holosko & Taylor, 1994). Social work in health care can trace its roots to 1905 when Dr Richard Cabot at Massachusetts General Hospital hired Ida Canon to provide assistance in the follow up care for patients he discharged from the hospital (Kitchen & Brook, 2005; Holosko & Taylor, 1994). Historically, referrals were only made to medical social workers if any of the following occurred: an identified need for child protection, identified psychosocial issues by a medical professional, arrangement of community services or a delay in the discharge due to identified social reasons (Kitchen & Brook, 2005; Zimmerman & Dabelko, 2007). Over time and through accretion, the initial medical social work roles have been maintained and new duties have been expanded to accommodate current issues (Holosko & Taylor, 1994). In addition to coordinating discharge arrangements, medical social workers may provide crisis intervention, abuse screenings, and assist patients with financial assistance programs (Zimmerman & Dabelko, 2007). Lesser (2000), found that social workers within the traditional medical model experienced narrow perceptions of their training and expertise, an emphasis on the physical illness and treatment, a lack of stability for funding social work positions, and professional isolation within the traditional medical model. While the medical social worker is well qualified to perform these various duties, this coordinator role leaves little time to provide traditional counseling activities and client advocacy (Zimmerman & Dabelko, 2007).

Literature supports the impracticality of the primary care physician's ability to assess for psychosocial problems, address treatment compliance issues, engage the family and make the appropriate community referrals (Lesser, 2000; Kitchen & Brook, 2005), while also tending to the medical disease, treatment and symptom management. However, historically, it has been found that many primary care providers are unaware of the ways in which social workers can

provide support and assistance (Kitchen & Brook, 2005; Zimmerman & Dabelko, 2007). It has been found that the collaboration with interdisciplinary and multidisciplinary team members provide early intervention and adaptations of treatment plans that improve continuity of care and ultimately strengthen the patient-physician relationship (Lesser, 2000; Zimmerman & Dabelko, 2007).

There is a trend in health care to move away from the traditional medical model toward a collaborative and integrated model of care that is a multidisciplinary team approach (Zimmerman & Dabelko, 2007). There are a variety of models of collaborative or integrated medical models of delivering health care that depend on the setting, social service and specialty services availability. O'Malley (2011) noted that depending on the level of support of the medical providers, not all programs work well. Their success will depend on their ability to focus on patient and family needs, recruitment of social work staff, as well as the patient's ability to participate in problem solving (Rosenthal, 2008).

Lesser (2000) examined a family medicine physician and social work collaborative model that resulted in a holistic approach to the primary care medical practice. This type of partnership has been found to be particularly compatible to support the bio-psychosocial aspects of disease and health management (Lesser, 2000). The physician emphasizes the possibility of mental health concerns while addressing the medical disease while the social worker emphasizes the medical concerns while addressing the psychological and social issues that may be contributing or resulting factors of the medical disease (Lesser, 2000). A study noted by Smith, et al., (as cited by Rosenthal, 2008), indicated that 80% of patients will accept management for psychological distress from their primary care providers and only 10% will follow through with a referral for psychological support, stressing the importance the primary care provider's role in

the success of the outcome. These statistics stress the importance of developing programs that provide full integration of mental health services into the primary medical clinic in order to improve outcomes in both of these areas (Rosenthal, 2008). According to Zimmerman and Dabelko (2007), the professional social work values that form the foundation for practice situate social workers in key positions to play leadership roles and help to foster the shift to a collaborative model of care. Some of these values include justice, dignity of worth of the person, the importance of human relationships and integrity (NASW, 2008).

Integrated models of medical care often provide comprehensive services that are broader in their scope than just providing preventative care or chronic disease management (Kitchen & Brook, 2005; Madsen, 2009). The team approach increases the number of contact points between the patient and the health care team in the management of preventative care as well as chronic illness (Rosenthal, 2008). Some of the expanded services are designed to address the needs of the patient and family and their living situation including work schedules and other demands that may affect follow through and compliance with medical advice, patient well-being and overall health (Kitchen & Brook, 2005; Rosenthal, 2008). Situations that may be considered include patients whose medical or social issues are considered high risk, the need for bio-psychoeducation and coordination of care (Kitchen & Brook, 2005).

Collaborative models of medical care have shown evidence of improved quality of care, coordination of services, decrease in medical errors and improved patient and family satisfaction (Zimmerman & Dabelko, 2007). By including patients and families in treatment and other health care decisions and recognizing their personal expertise, compliance rates could improve (Zimmerman & Dabelko, 2007). Social work services are being integrated in this collaborative type of care and have been shown to be valuable resources in meeting patient and family needs

in the primary care setting (Zimmerman & Dabelko, 2007; Zilberfein & Hurwitz, 2003). The unique needs of patients with advanced disease in the primary care setting challenge social workers to use skills beyond the traditional role of discharge planning (Zimmerman & Dabelko, 2007) and focus more on the subjective experience of the patient (Zilberfein & Hurwitz, 2003).

Social work training and education provide expertise to address a wide range of mental health problems in the medical clinic setting. Psychosocial problems that may arise in the primary care clinic may include family issues, adjustment disorders, work related stress, life transitions, marital problems, alcohol and other substance abuse, chronic illness and its impact on quality of life, grief issues and coordinating care for elderly patients (Lesser, 2000). Social work expertise and skills in advocacy help patients navigate both internally and externally through complex health care systems (Kitchen & Brook, 2005).

Social workers stress patient and family autonomy and empowerment (Zimmerman & Dabelko, 2007; Madsen, 2009). They have ability to help the patient navigate through the complex medical and community agency systems (Zimmerman & Dabelko, 2007); provide brief, solution focused interventions (Kitchen & Brook, 2005); and collaborate with other disciplines as it relates to various aspects of the management of illness (Kitchen & Brook, 2005). Other services provided by social workers in the integrated medical setting may be counseling patients in the development of short and long range planning such as preparation for nursing home or other long term placement, as well as facilitation of support groups as they have been found to be beneficial to certain patient populations (Lesser, 2000).

Social workers' holistic approach to care takes into consideration the patient's home environment, family involvement and inclusion of community resources (Kitchen & Brook, 2005; Madsen, 2009). The social worker is able to coordinate services that help to bridge the



gap between a patient's hospitalization and return to their "home" environment (Kitchen & Brook, 2005; Zimmerman & Dabelko, 2007). Interventions may include teaching family and caregivers how to access community resources on their own and encourage development of patient advocacy skills (Kitchen & Brook, 2005; Manis & Bodenhorn, 2006).

Furthermore, by having a social worker on the team provides easy accessibility as well as decreases stigma of social service involvement (Lesser, 2000). Having the social worker's office located in the medical clinic dramatically increases the likelihood of the patient following through with a social work referral (Lesser, 2000). Another factor that increases utilization of social services is the ability for joint appointments with the physician (Lesser, 2000; Rosenthal, 2008). As noted by Huntington, 50% of patients stated they would not have gone to see a social worker outside of the primary medical clinic setting (as cited by Lesser, 2000).

In a patient centered model of care, the patient identifies that problem and the treatment plan is designed with the active involvement of the patient rather than traditional medical care in which the provider identifies the problem and the course of treatment (Enguidanos, et al., 2005; Madsen, 2009). There is an emphasis on patient education (Enguidanos, et al., 2005). Additionally, the focus is on problem solving versus service coordination (Enguidanos, et al., 2005; Madsen, 2009). Joint appointments with the physician and social worker along with other interdisciplinary team members bring the appropriate providers to the patient instead of the traditional model of care in which the patient must accommodate the professional's schedule (Lesser, 2000; Rosenthal, 2008).

Additionally, in a collaborative medical setting, the physician, social worker and other team members usually meet on a routine basis to discuss patients. Formal and informal consultations may take place (Lesser, 2000). The social worker is able to create awareness of the

patient's identified psychosocial problems as well as discuss appropriate ways to approach the patient (Lesser, 2000; Durkin, et al., 2003; Holosko & Taylor, 1994). Moreover, social workers may also have opportunities to provide education and training to physicians and the interdisciplinary team on the psychosocial aspects of illness and techniques for interventions (Lesser, 2000; Holosko & Taylor, 1994). Kitchen and Brook (2005) interviewed medical students in a residency program who had the opportunity to work closely with social workers regarding their experiences. The survey results indicated that the residents felt they had more knowledge on cultural issues; family dynamics; impact of poverty; community and area resources; and patient self-determination than those medical students who did not have social workers on their teams.

Zimmerman and Dabelko (2007) reported that 50 % of patients in the United States fail to comply with their medical treatment care plans. The use of the collaborative medical model stresses autonomy, empowerment, family involvement in decision making, development of self-advocacy and self sufficiency skills which has been found to improve compliance rates to 85% (Zimmerman & Dabelko, 2007). According to Rosenthal (2008), 87% of primary care providers who were surveyed indicated that they believe an interdisciplinary team improves the quality of care. Literature suggests that outpatient follow up care was directly impacted by the presence of a social worker on the team. The follow up plan of care was adjusted due to identified social issues, family concerns and cultural factors (Kitchen & Brook, 2005). Other outcomes of social service interventions include increased involvement of the patient and family in decision making (Kitchen & Brook, 2005; Madsen, 2009).

## **The Role of Social Work in Treating Anxiety and Depression**

According to Manis and Bodenhorn (2000), there are several important tasks that patients who have terminal illnesses need to address including taking care of personal and business matters; coping with the loss of family; friends and self; arranging for medical care; short and long range planning; anticipatory grief work; and dealing with pre-existing psychological issues (Germain & Gitterman, 1980; Holosko & Taylor, 1994). Social work skill sets include the ability to engage and establish rapport with the patient, provide information on options, validate as well as challenge beliefs and behaviors through a limited period of time (Zimmerman & Dabelko, 2007). Social workers are adept in assisting patients with these tasks through their particular skill set, knowledge and use of bio-psycho-social values (Germain & Gitterman, 1980; Holosko & Taylor, 1994; Zimmerman & Dabelko, 2007).

Social workers are able to assume the primary responsibility for providing for the psychosocial needs of these patients (Lesser, 2000). A psychosocial assessment is completed to identify needs (Lesser, 2000; Kitchen & Brook, 2005; Holosko & Taylor, 1994). Interventions are then determined based on the needs and the resulting impact on patients quality of life (Durkin, et al., 2003; Holosko & Taylor, 1994). Interventions may include referrals to community services (Lesser, 2000; Zilberfein & Hurwitz, 2003; Kitchen & Brook, 2005); provision of counseling and psychotherapy (Vodermaier, et al., 2009; Lesser, 2000) and supplying psychoeducation to patients, families and healthcare providers (Kitchen & Brook, 2005; Zimmerman & Dabelko, 2007).

Social workers provide a valuable contribution to the terminal patient's care in addressing anxiety and depression. Counseling is an important aspect of working with these patients. The focus of counseling is to reduce the patient's level of anxiety and addressing their fears and

concerns such as fear of the unknown, loss of self-control, disability, loss of identity and loneliness (Manis & Bodenhorn, 2006). Counseling helps address the issues that inherently arise through the integration between trying to live and preparing to die. Examples include arranging final affairs, coping with losses (Holosko & Taylor, 1994; Manis & Bodenhorn, 2006), planning for future care needs and making treatment decisions (Manis & Bodenhorn, 2006). Counseling assists the patient to transition to the terminal phase of the disease trajectory when appropriate and assists the patient with having closure (Manis & Bodenhorn, 2006). Additionally, counseling addresses psychosocial issues such as interpersonal relationship problems or cultural, financial or environmental factors (Manis & Bodenhorn, 2006). Relaxation techniques, hypnosis and meditation also have a role in helping patients participate in managing their pain, anxiety and depression in non-pharmacological ways (Holosko & Taylor, 1994).

Enguidanos, et al., (2005) studied an integrated depression case management model of care that provided treatment for depression in late life. This approach was patient centered and involved the patient in determining treatment goals and the development of interventions. Through the utilization of a problem solving model, patients were able to gain new perspectives and were willing to explore resource options (Enguidanos, et al., 2005). This approach included direct communication with the primary care provider regarding patient identified treatment compliance barriers, referral to appropriate community resources, facilitation of family meetings, identification of safety concerns and the need for long term care planning (Enguidanos, et al., 2005; Babcock & Robinson, 2011).

Another collaborative team format was examined by Babcock and Robinson (2011), in which a palliative care program developed “transitions counselors” that tended to the psychosocial needs of patients and families in the hospital through family therapy. These

counselors provided family meetings, patient and family education on the disease trajectory and ensured patient and family members understood the views of multiple medical providers (Babcock & Robinson, 2011). This program was based on a communication model of care between the patient, family physician and health care team. They focused on clarifying goals of care, coordinated services, provided mediation and managed conflicts between the patient, family and health care providers (Babcock & Robinson, 2011).

Medical social workers have several theoretical frameworks in which they provide much of their practice. The person-in-environment and systems theories (Kitchen & Brook, 2005; Holosko & Taylor, 1994) provide a basis for social work intervention. Through these perspectives, social workers are able to help the health care team see the patient as part of a family system (Zilberfein & Hurwitz, 2003; Madsen, 2009) Social workers also often utilize a strengths perspective (Pratt-Hopp, Thorton, & Martin, 2010; Zimmerman & Dabelko, 2007; Madsen, 2009). Brief, solution focused therapy (Kitchen & Brook, 2005; Madsen, 2009) is often essential in medical social work due to the short term nature of the social worker-patient relationship in hospitalized or palliative care patients. Motivational interviewing is another technique than may be applied in certain circumstances (Madsen, 2009).

The terminally ill patient is likely to experience grief due to effects of illness such as their job, disability, loss of family role and independence as well as to the anticipated future losses of their life and personal relationships which can result in depression (Manis & Bodenhorn, 2006). A counselor can help examine expressions of grief (Holosko & Taylor, 1994) and can explore spiritual meanings (Manis & Bodenhorn, 2006).

Many medical social workers provide case-management which blends well with the collaborative model of care (Kitchen & Brook, 2005). Therefore, the social work and primary

care provider partnership can allow for early assessment and intervention for the complex emotional and social issues that arise in this patient population (Babcock & Robinson, 2011; Zilberfein & Hurwitz, 2003). The literature suggests that it is essential for primary care physicians to utilize social workers and their skill set to address the complex psychosocial aspects of the terminal illness in their palliative care patients (Lesser, 2000) and that once they have been exposed to partnering with a social worker that they will be long term patient and social work advocates (Kitchen & Brook, 2005).

### **Research Question**

As reported in the literature, there are many challenges in identifying and treating anxiety and depression in patients who have terminal illnesses. There is a wide variation of prevalence rates due to a lack of standardized screening and assessment tools in this population. A number of barriers preclude identification of psychological distress as a result of physician bias and lack of training as well as patient non-disclosure of symptom information. While there is a lack of attention to the issue of anxiety and depression among these patients, when treatment is prescribed, recommendations include medication, psychotherapy and/or patient education.

Lack of attention to symptoms of psychological distress creates many additional complexities to the care of patients with advanced disease. Undiagnosed and untreated or undertreated anxiety and depression decreases the patient's performance status (Gore, et al., 2000; Fitzsimons, et al., 2007); diminishes the patient's ability to make good treatment decisions (Block, 2000); limits their ability to interact with family and friends (Lloyd-Williams & Friedman, 2001; Hill, et al., 2008); and ultimately decreases the patients overall quality of life (Block, 20010). There is a sense of urgency in the need to address psychological distress for patients who had advanced disease in that their life expectancy is short and often times,

depression is identified within the last 4-6 weeks of their life (Lloyd-Williams, 2001).

Undiagnosed and untreated depression at the end of life affects the patient's ability to participate in important end of life decision making and activities that provide closure (Manis & Bodenhorn, 2006; McCoubrie & Davies, 2006). Additionally, untreated psychological distress affects treatment compliance (McCoubrie & Davies, 2006; Robinson & Crawford, 2005), increases difficulty in managing pain and other symptoms (Zeiss, et al., 1996), increases hospitalization rates and length of stays (Kelly, et al, 2006), and limits the physician's ability to care for these patients (Payne, et al., 2007).

The trend in healthcare is moving away from the traditional medical model toward a more collaborative approach that utilizes social work services in a more comprehensive manner. As noted by Holosko and Taylor (1994), health care is the single largest field of practice for social workers. Therefore, the movement toward collaborative medical care will place social workers in a strong position to tend to the psychosocial issues that impact terminally ill patients, including anxiety and depression in a way that has not been feasible in the past. However, despite the progress has been made, there are still a large percentage of patients with advanced disease who experience psychological distress and left untreated.

There is a gap in the way traditional medical care is provided, especially in regard to anxiety and depression in patients with advanced disease resulting in the trend to move toward a more collaborative approach to medical care. Studies have been done to determine how providers assess for and treat anxiety and depression in patients with advanced disease, but little research has been done to examine why medical providers do what they do and why patients are not getting what they need.

The issue of anxiety and depression in patients who have advanced disease is particularly important for social workers. Due to the fact that social workers work in a variety of settings that serve this patient population, further research about the use of social work in palliative care is needed to ensure that palliative patients' psychological distress is being addressed as appropriately as possible. Further research is needed to explore the relationship between how primary care providers identify anxiety and depression in palliative care patients and their usage of social work and mental health services. Therefore, research questions for this study are to 1) describe how primary care physicians assess and identify anxiety and depression in patients with advanced disease; 2) to discuss what treatment methods are predominantly used for treating anxiety and depression in this population; and 3) to illustrate to what extent social work and mental health services are currently being utilized in a specific care setting to address these psychological issues.

### **Conceptual Framework**

There are several theoretical frameworks that relate to this study. Erikson's theory on psychosocial development applies to the palliative population and how they respond to the diagnosis of a terminal diagnosis. The integrated model of medical care illustrates collaboration of a multidisciplinary team in caring for patients who have advanced illness to reduce distress by relieving symptoms and improving overall quality of life.

#### **Life Cycle Theory**

Erik Erikson developed the theory of psychosocial development, often referred to as the Life Cycle Model or life stages ("Theory of Psychosocial Development", 2011; Germain & Gitterman, 1980). This theory provides an explanation of the developmental tasks that trigger an



internal crisis in which individuals either has resolution and experiences cognitive and instinctual growth or regression (“Theory of Psychosocial Development”, 2011; Boeree, 1997).

The eight stages of development throughout the life cycle include trust versus mistrust; autonomy versus shame and doubt; initiative versus guilt; industry versus inferiority; intimacy versus isolation; generativity versus stagnation; and integrity versus despair (“Theory of Psychosocial Development”, 2011; Boeree, 1997). Erikson believed that each of these life stages allow individuals to develop specific virtues such as hope, determination, purpose or courage, competence, loyalty, love, care and wisdom which were viewed as inherent strengths (“Theory of Psychosocial Development”, 2011; Boeree, 1997). Individuals who were not able to resolve the inner conflict for each of these stages were likely to develop psychopathological disorders such as addictions, depression, paranoia, obsessions, compulsions, schizophrenia and personality disorders (“Theory of Psychosocial Development”, 2011).

The Life Cycle theory has several implications for people who have advanced illness. For individuals who had difficulty at any of these life stages, there is impact on their ability to cope with the diagnosis of a terminal illness, treatment side effects, functional impairments, as well as facing their mortality (“Theory of Psychosocial Development”, 2011; Boeree, 1997). For example, if an infant does not experience the ability to trust their care provider they are less likely to develop hope and faith which will create difficulties in getting through disappointments later in life (Boeree, 1997). If a toddler is discouraged from experiencing autonomy, the virtue of willpower or determination is not nurtured which will affect issues of shame and doubt as an adult (Boeree, 1997). The final stage of development involves the task of developing ego integrity. During this life stage there is usually a significant amount of despair: retirement and loss of usefulness or purpose; the development of serious illnesses; and there are concerns of

death such as a spouse or friends. Those who pass through this stage well develop the virtue of wisdom and those who struggle are more likely to develop depression (Boeree, 1997).

The life model theoretical framework has implications for this study in that patients who have advanced illness are more likely to experience stressful events that result in anxiety and depression. It is important for the primary care provider as well as the social worker to have an understanding of the tasks of development in order to provide the best support and intervention throughout the disease trajectory. For those patients who are having particular difficulty coping with their diagnosis or functional status changes as a result of their medical condition, medication side effects or somatic symptoms may be in need of specialized attention to process these experiences (Germain & Gitterman, 1980) and possibly rework these earlier experiences with a therapist (“Theory of Psychosocial Development”, 2011).

### **Collaborative Medical Care**

There is a shift in healthcare toward a more collaborative and integrated approach to patient care (Zimmerman & Dabelko, 2007). Research has indicated that a collaborative approach to care has been found to provide significant benefits to patients who have depression, anxiety, poorly controlled symptoms, and terminal illness among others (O’Malley, 2011). This approach may vary across institutions but fundamentally the goal is to incorporate a more patient centered type of care that utilizes social work and mental health staff as integral team members which allows for continuity of care and increases physician awareness of psychosocial issues that may impact the patient’s medical disease (Rosenthal, 2008; Zimmerman & Dabelko, 2007; Roundy, et al., 2005).

The approach allows the physician to treat the medical disease and physical symptoms, mental health staff can tend to the in-depth assessment of the patient’s mood, decision making

capacity and judgment and the social worker can provide input regarding the patient's support system and coping skills. The team may also include other members such as spiritual services, dietician, and other ancillary staff as needed (Block, 2000; Akechi, et al., 2004; Strozier & Walsh, 1998). The various team members may ebb and flow depending on the patient's ever changing needs (Rosenthal, 2008).

Within an integrated model of care, the primary care physician does not need to specialize in mental health services but allows for the patient to access and partner with the appropriate team member for adequate symptom management (Eisenberg, 1992; Periyakoil & Hallenbeck, 2002; Lloyd-Williams, 2003). Continuity of care is improved, allowing for the primary care provider to have an increase awareness of how the patient's psychosocial issues are impacting their quality of life (Rosenthal, 2008). A social worker may assess for psychosocial distress throughout the disease trajectory, recognizing times in which the patient may be having more depressive or anxiety symptoms and instituting treatment in a timely fashion (Rosenthal, 2008; Zimmerman & Dabelko, 2007). Referrals may be made to psychiatry in cases in which the patient is not responding to medication or supportive treatment, when complex co-morbid conditions or physical disease impacts medication choices or when the patient has expressed suicide ideation (Hill, et al., 2008; O'Malley, 2011).

Research suggests several basic foundations for evidence based care focusing on patient safety, patient centeredness, effectiveness and timeliness of medical interventions, and equity (Zimmerman & Dabelko, 2007). One particular model of care is being implemented in many primary care settings across the United States, often called a patient-centered home medical model of care (Zimmerman & Dabelko, 2007; O'Malley, 2011). The integrated approach to care

includes the patient and family as active participants in medical decision making as well as including the entire bio-psychosocial experience of the patient (Zimmerman & Dabelko, 2007).

Social workers have long held the view of the importance of the whole person and their experience with medical disease (Holosko & Taylor, 1994), integrating a team approach to care in their practice (Holosko & Taylor, 1994; Zimmerman & Dabelko, 2007). By utilizing a team approach, the social worker and primary care provider are able to develop a partnership for providing holistic care to the patient (Lesser, 2000). Often by working with physicians on difficult psychosocial issues, social workers are able to break the barriers of the traditional medical model and move toward a team based approach to patient care (Kitchen & Brook, 2005; Zimmerman & Dabelko, 2007).

## **Methods**

### **Research Design**

This study is a one time, qualitative interview using a semi-structured interview format. The focus of this study is to examine the process that physicians use to identify anxiety and depression in patients with advanced diseases and to further understand their methods of treating these mental health issues including their utilization of social work and mental health services to treat these patients. A qualitative approach is felt to be the best research design to gain understanding of the processes and potential barriers for the patient to receive effective treatment given the complexities of assessing and treating anxiety and depression in patients with advanced medical diseases.

### **Sample**

The sample for this study will include primary care providers who are Internal Medicine and Family Practice Physicians, as well as Advance Practice Nurses and Physician Assistants

who are currently employed and practicing medicine in two small rural clinics. One clinic is currently piloting a patient centered home medical model of care which employs the interdisciplinary team approach to care and includes social workers on the team. The other clinic follows the traditional medical model approach to care.

This is a non-probability, purposive and convenient sample. Non-probability means that the researcher does not choose participants randomly (which would require having the names of the entire population of relevant people from which to choose), but rather chooses people based on some method, in this case convenience (Monette, Sullivan & DeJong, 2011). A purposive sample is one that is chosen because of participants' area of expertise or experience with the subject matter (Monette, et al., 2011). The sample is also convenient due to their location to the researcher.

### **Protection of Human Subjects**

In compliance with the Institutional Review Board (IRB) and Protection of Human Subject requirements as well as the University of St. Thomas and St. Catherine University School of Social Work program, a consent form will be reviewed and signed by the respondents prior to commencement of the interviews. The consent form, attached and labeled Appendix A, addresses issues of confidentiality, storage and destruction of the audiotape and identifying data.

Potential research participants will be recruited on an individual basis; however, they will be informed of this research project at one of their department meetings prior to individual contacts. At this department meeting they will be informed that participation in this study is voluntary and that there is no obligation to participate. Furthermore, respondents will be informed that their participation will not be shared with any other staff member of the clinic or medical institution. The researcher will follow-up with an email to the primary care providers at

both clinics in recruitment efforts. The researcher has no power over potential participants: she is not their supervisor or evaluator. A copy of the researcher's script for the recruitment department meeting and follow up contacts is attached and labeled Appendix B.

Respondents who participate in this study will be informed that their contributions to this study will be kept confidential. Participation is voluntary. There are neither risks nor direct benefits for participating in this study. Respondents will be informed they can terminate the interview at any point. Additionally, the respondents will be informed that if they decide to participate and later decide to withdraw from the study, they can notify the researcher within one week of the study to have their data withdrawn. Furthermore, respondents will be informed that all interviews will be audiotaped and transcribed verbatim for data analysis prior to commencement of the interview. Respondents will be informed that the data collected would be shared at the Spring Clinical Research Presentations and that only the data will be shared, their names and identities will remain confidential. The respondents will also be informed that the audiotapes will be destroyed no later than June 1, 2012 and transcripts will be kept indefinitely. To ensure confidentiality, the research records, data and audiotaped interviews will be kept in a locked file and password protected computer in the researcher's home. Interviews will take place in a location of the respondent's choice to protect confidentiality of their participation in this study.

To further protect the participants of this research, the proposal for this study will also be reviewed and approved by the IRB for Ministry Health Care, the corporate office for the clinics where the physicians are employed. This IRB approval letter is attached and labeled as Appendix C. In addition to the IRB approval, a letter of support for participation in this study

will be signed by the Regional Vice President of the Ministry Medical Group where the physicians are employed (Appendix D).

### **Data Collection**

The structure for the interview questions has been developed based on the literature review findings (Appendix E) keeping in mind the purpose of this research and identified research questions. The semi-standardized format includes some predetermined questions but allows for the researcher to ask additional questions for clarification or to get additional information (Berg, 2009).

The interview will consist of 15 questions which were reviewed and approved by the Research Chair and the researcher's Clinical Research Committee. The initial questions are general in nature, inquiring about the respondent's educational and medical practice history. They then become more specific as the interview progresses in order to gather data surrounding the complexities of identifying and addressing anxiety and depression in patients with advanced diseases.

The interview schedule, sequencing and content of questions include inquiring about the respondent's experience, knowledge, observations and opinions about the issue of anxiety and depression in patients with advanced disease. There are seven questions that inquire about the respondent's process for identifying anxiety and depression in their patients with advanced medical diseases and their preferred methods for treatment of these mental illness disorders. Two of the questions ask about how the respondent's patient caseload is impacted by anxiety and depressive disorders. There is one question that explores the respondent's process for utilizing social work and mental health services. The remaining questions allow for the respondent to identify barriers or comment on suggestions that they feel would be helpful in their practice to

assist palliative patients with anxiety and depression. The interviews will be audiotaped to allow for verbatim transcription at a later date for data analysis.

### **Data Analysis**

The audiotaped interviews will be transcribed verbatim in order to conduct grounded theory data analysis by this researcher. Grounded theory is the data analysis technique that will be employed for this research. Grounded theory combines data collection, analysis and development of the theory at the same time. The theory develops through direct observations, field notes, data collection, data analysis and identification of variables (Berg, 2009). A line by line review of the transcription will be completed to identify codes. The researcher will utilize the open coding process which involves four steps. The first step is to ask the data questions in how it relates to the research question. Second, the data is analyzed in great detail at first so the data is saturated with repetitious codes. Third, notes are made of ideas that emerged during the coding process that may lead to theories later on in the data analysis. The fourth step is to be aware that even perceived mundane variables may provide valuable information in the analysis process (Berg, 2009). Coding is the process of sorting the data (in this study the data is the interview verbatim transcription) and simplifying it by using the respondent's words, whether it be a single word or phrase, in order to identify themes based on what was determined to be the important parts of what was said by the respondent (Monette, et al., 2011). The transcript will be read a second and third time to complete line by line coding and then the codes will be grouped into themes. Any code with at least three independent examples found within the data will be considered to be a theme (Berg, 2009).



## Findings

The purpose of this study was to look at how primary care providers assess anxiety and depression in patients with advanced disease, as well as how they utilize treatment methods, especially their usage of social work and mental health services. Several themes were identified in the literature review, which were mostly reflected in the data of this study. Issues such as time factors, physician discomfort, and lack of mental health accessibility were among the identified themes. Several themes arose in this study that were not as predominant in the literature review; there was little emphasis of productivity quota pressure, however there was significant support for the use of social work services.

Primary care providers at two rural clinics in Northern Wisconsin were invited to participate in this study. The primary care providers included Family Practice and Internal Medicine Physicians, Nurse Practitioners and Physician Assistants who provide primary care to patients with a variety of illnesses, including patients who have advanced stages of disease. Out of a total of 23 providers between the two clinics, 10 providers agreed to participate in this study; however only nine were actually interviewed. One interview was not able to take place due to scheduling conflicts. All of the participants were from one of the two targeted clinics. There were no volunteers from the other clinic. The clinic in which there were no participants was the clinic that is currently piloting the Patient Centered Medical Home Model of care. Among this group of study participants, there is a total of 210 years of combined experience in practicing medicine. All of these providers have spent the majority, if not all, of their medical practice in this community and the clinic's associated branch offices in surrounding communities. Eight of the nine participants spent their entire careers in rural settings.

## Identification of Palliative Patients

All of the participants in this study were primary care providers in Internal Medicine and Family Practice. They see patients with a variety of illnesses, including patients who have advanced diseases. One theme that arose during this study is the fact that some of the participants did not recognize that they see palliative care patients in the clinic setting. This was an important finding and was not expected.

*“Typically I don’t see palliative patients in the office all that much.”*

*“You know I really don’t see palliative patients in the clinic very often...mostly in the nursing homes.”*

*“When you look at my palliative care patients they sit into two categories because I don’t have more than maybe a handful of outpatient patients that are palliative care...quite a few of the nursing home patients...the other group that I end up acquiring is a lot of the hospice patients.”*

One study participant fully acknowledged the amount of palliative patients within their medical practice.

*“Most of my practice are older folks and they all, virtually everyone, has advanced disease of some sort...not a lot of them that are terminal in the next 6 months.”*

These research participants reported that they work with mainly nursing home and hospice patients which are outside of their clinic practice. Seven of the participants recognized that they have patients with a variety of illnesses and many of their patients are older and have

chronic and advanced diseases. There could be a discrepancy in identification of palliative patients due to the participant's as well as the researcher's definition of "palliative care".

### **Prevalence of Anxiety and Depression among Patients at End of Life**

The participants of this study were asked about the percentage of their patients who have anxiety and depression at the end of life and to indicate how much of an issue it is for their patients. Seven out of nine participants indicated that between 50% and 80% of their patients did experience some significant level of anxiety and depression at the end of life.

*"I think it's a big issue. I think the majority of patients, a percentage, probably, ballpark 75%."*

*"Almost everybody has anxiety and depression at the end of life, pretty much everybody I see at the end of life do, but not everybody wants to be treated or needs to be treated."*

*"There are some patients who are very comfortable at the end of life and there are others who are definitely not. Percentage of people who are comfortable, probably about half."*

*"You know that there is a huge spectrum of people's reactions to end of life and for some it's terribly traumatic with anxiety and fear and depression and other people seem to take it just as a part of the progression of life. I haven't measured this but I think half of the people are well adjusted to accepting end of life and half are not."*

One provider had a different view point by recognizing that patients have more strengths than we give them credit for.

*“I would conservatively say that few people seem to have as severe of issues as I would think they would have. They seem to handle it better than I think would. I would think that maybe 25% of them might be candidates, in my mind, for some sort of medication to help them.”*

Most of the participants of this study indicated that the majority, if not all, patients experience some anxiety and depression at the end of life. These estimates are based on very informal impressions and were not formally measured, so they could be incorrect, however, they are an indication of the possible scope of the issue. Many of the participants indicated that not all of their patients require any formal intervention for their anxiety and depression.

**Patient support systems and coping mechanisms.** Several participants addressed the fact that while a majority of their patients may experience anxiety and depression at the end of their life, not all of them require any formal intervention. The research findings indicate that patients who have good coping mechanisms and support systems tend to manage their anxiety, depression, and preparation for end of life better than others who are more isolated.

*“I’m amazed at how well most patients handle it...a lot of times by the time patients come to see us you know they know what’s going on and we’re not hitting them over the head with something they don’t already know. It’s surprising, I think of two terminal patients that I saw that hadn’t come in to see the doctor with very similar conditions of metastatic cancer and they were probably 95% sure of what was going on before they came in and they just needed the confirmation and you wonder how you’re gonna gently tell them, but you don’t have to worry about that because you know they know they just need the confirmation and then they can get on with what they have to do. That’s an interesting observation for me.”*

*“A lot has to do with family members, who their support people are, if they have any. Those with family seem to handle this much better. Those without family, you have to devote special attention to because they really feel alone.”*

*“A lot of my elderly patients have made it very clear long before we get there that they prefer not to have aggressive measures taken and so forth and they have some acceptance toward it.”*

*“Sometimes ...these are not issues and never need attention. And other people, it’s a continual battle, depends upon how they progress through life.”*

According to this research, patients who have good support systems (usually family) and coping mechanisms tend to get through the anxiety and depression related to end of life better than patients who have underlying mental health issues or limited family and/or community support.

## **Education**

In this study the majority of the participants indicated that they had not received any formal education in the area of anxiety and depression in patients with advanced disease.

*“I don’t think I’ve ever received any formal training.”*

*“Not specifically in end stage diseases, no.”*

*“Other than medical school and continuing medical education, none.”*

Only one of the providers indicated that they had received some training in addressing anxiety and depression.

*“During our residency, we saw many people with lots of end stage diseases, cancer and we had geriatric rotations.”*

All of the research participants indicated that they engaged in ongoing, informal education through Continuing Medical Education (CME) seminars and online training in the area of anxiety and depression. The majority of the participants indicated that they have read professional journal articles on anxiety and depression in the past five years, but most were not specifically geared toward the palliative care patient.

*“I don’t believe I have ever been to any workshops or conferences, there may have been over the course the years some CME presentations.”*

*“CME’s...more just the emotional issues”* [and not specifically on anxiety and depression in advance disease].

*“Nothing other than my own study of literature of current medical problems and management of office patients. I don’t have any education specifically. I attend post-graduate education lectures all the time and I’ve attended those regarding anxiety, depression and end of life care but I don’t have any degree in that.”*

*“I’m sure that I’ve attended a couple CME’s for maybe an hour or two but not a focal workshop specifically toward that.”*

*“Other than lectures, periodically, over the years, either sponsored here through our CME program or as a part of general medicine CME program I haven’t had any other specific training, although these lectures were at times related specifically to anxiety and depression.”*

Seven of the nine participants have been practicing medicine for many years and did not receive any formal training on anxiety and depression during residency; however, the remaining participants have newer practices and stated they had some exposure to these issues during their residency training. All of the participants in this study have actively pursued additional education and information on their own through attending conferences, continuing medical education workshops and reading current literature. Although these primary care providers have engaged in some form of continuing education on anxiety and depression they haven't focused on its specific manifestation and treatment at end of life.

### **Provider Level of Comfort in Addressing Anxiety and Depression in Palliative Patients**

Study participants were asked to describe their level of comfort in assessing as well as treating anxiety and depression in patients with advanced disease. The responses varied and many of the participants indicated that they felt very comfortable with both of these areas. However, some of the participants acknowledged areas that they may struggle with, but do because the patient needs care.

*"I would say my comfort level is average. I'm not terribly comfortable with it. ...It's not an issue that I feel particularly skillful at dealing with or addressing. I do think it's something that's important so I do it but don't think that I have a tremendous ability to affect people's outcome simply or by things that I have to say. So I tend to feel a little bit inadequate with it but I think that's fairly common."*

*"I'm pretty comfortable with it. We talk about end of life a lot in my practice."*

*"It's much better in younger people than it is in palliative care people. Because ...in younger folks it's fairly easy to identify and their forthcoming with things. In palliative care, for*

*me it's harder to identify because you can't tell if they're having overall depression related to the process or is there underlying issues creating that and sorting through that is hard."*

*"Well, I feel very comfortable in identifying the situation. I'm not quite as comfortable in treating them all of the time. I wish we had better choices of medication to treat with."*

Most of the participants indicated that they are fairly comfortable in both identifying and treating anxiety and depression in their patients. Some stated that it is much easier when the patient has clear symptoms or is reporting symptoms of emotional distress. A couple participants acknowledged some limitations in their comfort level as well as available treatment options.

*"...tends to be difficult to get a good outcome for some people and I have a certain level of personal frustration with that...a personal lack of comfort in dealing with that."*

*"I'm not a great psychiatrist type person and specifically I had said I wasn't going to do that but I end up in it more that I want."*

These providers were able to acknowledge that they did not necessarily feel completely comfortable assessing and treating patients with anxiety and depression with advanced disease. However, they reported that they do it because they want to provide good care for their patients and want to ensure that these needs are being met as much as possible, especially for those patients who refuse to go to a mental health provider for these issues.

## **Screening Process**

The participants in the study were asked if they routinely screened their patients for anxiety and depression and to identify how much time was spent on these emotional issues



during an office visit. Each of the participants indicated that they spent some time on emotional issues but that the amount of time varied according to the patient's needs.

*“It does get addressed, not formally or not as a matter of routine necessarily, but certainly if they bring it up or if I have reason to suspect it's an issue for them. Then I will address it.”*

*“For those I deem appropriate, yes.”*

*“I would say that it's 50% or more of the time in the office visits that take care of emotional needs as medical.”*

All of the participants in this research study reported that they will spend some time on assessing any emotional distress that the patient may be experiencing at that time. They also reported that the amount of time will vary depending on the patient's needs. If there are more emotional needs than medical then the time will get spent on their feelings of anxiety, depression and fears. If there are more medical issues, then the majority of the visit is spent on addressing better symptom management or control of disease.

**Signs and symptoms of anxiety and depression.** There are two types of diagnostic criteria that are used to assist in the identification of anxiety and depression. They include the DSM IV-TR (mental health focus) and the ICD-10 (medical disease focus). The research participants were asked what symptoms help them to identify emotional distress in their patients.

*“Talking with the patient about their feelings and then look at how they're sleeping, how they're eating, pain, behaviors maybe the staff observe if they're a nursing home patient.”*

*“Sleep patterns, that typical inability to sleep; up awake; if they are ambulatory, pacing, moving around more at night; more mood swings, you know, irritation; pain issues out of control with what’s going on. Those are the markers that help. I think those are the main things.”*

*“Train of thought, you know, inability to carry on a normal thought process despite not having illness to the point it should affect it. In other words, something commensurate with the ability to carry on the thought process that’s disrupted and disoriented. That probably would be the first sign that they’re depressed.”*

*“Difficulty sleeping, difficulty concentrating, overall mood, getting along with family members.”*

*“Well number one is somaticism. If I see a person complaining about a variety of things every time they come in, you know you start asking questions: Are you worried about this or that? How can we reassure you about this? I don’t think you have this or that. You know, we’ve done this testing, this shows no evidence of this.”*

*“Insomnia. I almost always ask are you sleeping ok? Or do you have a sleep problem? Are you sleeping during the day? Agitation. Heart rate. Are you getting panic attacks and they describe what those might be. You know, you’re not resorting to alcohol or other drugs to help cope with this [are you]?”*

The primary symptoms that these participants considered triggers for anxiety and depression include changes in sleep patterns and thought processes; mood swings and other somatic complaints. Some of the participants mentioned that pain may be affected by anxiety and depression and also at times psychological distress may manifest in behavior changes.

Another participant raised the issue of patients using alcohol and/or drugs as a way of coping with their anxiety and depression.

**Assessment tools.** Once a medical provider suspects that there may be issues of anxiety and depression and decides to address it, there is usually some type of screening or assessment process. The providers in this study were asked several questions that addressed their assessment process, including the use of standardized assessment tools. Six of the nine study participants indicated that they do not use any formal or standardized assessment tools. They indicated that they use their intuition and medical judgment as well as patient, family and other staff reporting to identify signs and symptoms of anxiety and depression. When asked whether they use a formal assessment tool, respondents stated:

*“I don’t use those [standardized tools] as a rule. I tend to use personal observation. I tend to use reporting from family members or staff or I tend to use patient initiated reporting rather than any particular scale.”*

*“I just have my own set of questions depending on the person. Usually these are people that I know very well and are not people that are new to my practice so I just sort of know what questions and it varies person to person. I do not give questionnaires.”*

*“Well, I often ask if people have questions like that. Sometimes I can tell just by the way they are behaving, and some, probably fairly frequently, it’s brought to my attention by a phone call from a family member or friend prior to the appointment.”*

[Questions are] *“individual based on their problems. I kind of focus it on, you know, if it’s heart disease or dementia.”*

*“No, not in people who are well known to me. I don’t.”*

The remaining four participants indicated that they use formal, standardized tools in some situations but not necessarily for every patient.

*“If somebody comes in for just evaluation of things I use different tools.... I have a questionnaire for them basically to see if it is an issue just with anxiety or depression or if there is some other mental disorder. That is what I use for other patients.”*

*“I use the PHQ-9...not just for my palliative patients but for all of my patients with depression and anxiety issues. I also use it for all annual physicals.”*

*“I have used the Beck but I probably use the GDS [Geriatric Depression Scale] more often. I’m not satisfied with that.”*

*“The Beck Depression Scale is the one I have a copy of. I usually have them fill that out.”*

The findings of this study indicate that the majority of these participants tend to rely not only on their own medical judgment, but also take into consideration patient and family reporting as well as the assessments of other professionals such as nursing home, hospice and home health nurses. Many of these providers have been practicing for a number of years and have gotten to know their patients very well over the course of time; they state that this history with their patient helps to determine their course of action when one of their patients has developed a serious medical disease or recurrent disease.

While many of the participants indicated that patients or families will self-report issues of anxiety and depression, this research found that not all patients recognize that they are experiencing any emotional issues. One participant had something else to add.

*“I think it manifests as something else...Sometimes you know, I’ll talk with the patient to see what their perception is, but sometimes they don’t see that it’s an issue but it manifests in other ways, I think.”*

Another participant discussed the issue that patients and families may feel that emotional distress is normal and expected. As a result of this belief patients may not bring the issue up to the medical provider.

*“The family or patient may just resign themselves to the fact that I’m going to be gone anyway or they’re going to be gone anyway, it looks like its just part of the disease process.”*

There are times in which the patient will self report feelings of anxiety or depression, however the findings of this research indicated that sometimes the emotional distress will manifest in behaviors, acting out, irritability, and other ways that are not always easily defined. Furthermore, patients may not bring the topic up due to belief that these feelings are a normal and expected part of the disease and dying process.

**Ongoing assessments.** The participants in this study were asked if their approach in addressing anxiety and depression changes as the patient’s disease progresses. Several of the participants stated that they did not think that their process changed as the patient’s disease or needs changed and that they routinely assess for these issues at every visit.

*“I don’t think so.”*

*“I don’t think my approach changes, I mean, I think I base how much I delve into it based on how much I perceive anxiety and/or depression.”*

*“It might become a little more aggressive. I don’t think that overall method of treatment or involvement that I have with the patient would necessarily increase if the patient’s disease is increased unless the patient’s emotional needs change along with it.”*

When asked about whether their assessment process changed when a patient’s disease has progressed, these respondents stated:

*“Yes, I would say it does, because you are no longer focusing on long term management of these issues, but more acute, short term management of these issues. And it’s a bit different discussion.”*

*“It could. It depends on what I think is important. Sometimes people are just...these are not issues and never need attention. And other people it’s a continual battle. It depends upon how they progress through life.”*

*“I think the primary difference would be depending upon how they would potentially respond to medication treatment or discussion. And it has to do with their level of awareness or desire for treatment [for their disease] because at some point they are going to not want to do anything more or they realize they have maybe deeper things to worry about.”*

*“Identifying, more direct, if people come in with symptoms, yes there is no question”*

A couple of the participants indicated that they rely on other staff, such as nursing home, hospice, or home health nurses to identify patients’ emotional needs with advance disease, especially since these types of palliative patients do not come into the clinic often.

*“No not really, like I say, most of my patients are in the nursing home where the nurses will normally pick up things and feed them to me or like I say in hospice where I generally don’t even see them anymore.”*

Ongoing assessment of anxiety and depression in this population of patients takes place in a variety of ways. Some of the participants rely on patient or family self-reporting; others use their own clinical judgment and observation and in many cases the ongoing assessment is being done by other health care providers, typically nurses in the nursing homes, hospice and home health programs and reports are made to the provider for direction on treatment.

**Office visit outcome.** The participants were asked how addressing anxiety and depression during the office visit affected the overall outcome of the visit. The majority of the participants indicated that usually the outcome was positive for the patient, family, and provider. They discussed the importance of creating awareness of any emotional distress as well as acknowledging the patient’s emotional reaction in relation to their disease process.

*“It’s usually a positive variable on the outcome of the office visit.”*

*“I think the primary benefit of it, of getting it out, is at least helping the other family members to become aware of it. That seems to be the biggest benefit of it.”*

*“...they feel appreciative that you understand that they are anxious about this. And you know sometimes they are anxious for no good reason and others, they’re anxious for a significant reason. You try to give them as much information as you can about where this is gonna go and what services could be offered if things get worse.”*

*“I think it’s very positive. I think that patients want to talk about certain things and I’m happy to discuss it with them if they want to.”*

The research participants reported that addressing anxiety and depression is good medical practice. The majority of them indicated that the overall outcome of the office visit was positive when these issues were addressed. In addition, they recounted stories that the patients had expressed appreciation when the medical provider spent time addressing their emotional issues.

### **Treatment Methods**

The majority of the participants in this study indicated that they ideally would use a combination of medication as well as counseling to treat anxiety and depression in their patients. However, several of the participants identified that many patients are not open to going to a counselor and prefer to receive their treatment from the medical provider.

*“Ideally, I think it would be a combination of medication and counseling. Many times it ends up being mostly an attempt to help people medicate some of the feelings that their having and that’s in large part because many people, it seems to me, are reluctant to have counseling or go along with counseling.”*

*“For anxiety and depression in anyone, not just people at end of life, preferred is some sort of psychological management of the issues and try to get this out in the open and try to address these issues and resolve them. So I use counseling for that or somebody...in palliative care, very helpful in helping patients. We use drugs just as an adjunct to that. Whereas for depression, I’m more apt to go to medication.”*



*“It depends on part on what the issues are. If there’s a lot of anxiety about the situation, how they’re going to handle it and so forth, counseling is clearly going to work better than medications. Frequently if these patients appear to have been depressed long before they got into palliative care ...medications have a place. And usually it’s a matter of negotiating with the patients because frequently counseling is not something they will do, sometimes medication is not something they’ll do.”*

While the study participants indicated that a combination of medication and counseling would be the ideal treatment, not all patients are amenable to going to a counselor, and some patients will not take any medications.

A couple participants reminded the researcher that not all people need formal mental health support.

*“Well again it depends on the person. A lot of people don’t need it, they can approach end of life with their own resources and don’t need it but a lot of people need help so I try to individualize what I use.”*

The treatment interventions are individualized to each patient’s need based on their relationship with their medical provider, their family and community support and other inner resources and coping mechanisms. The study participants acknowledged that not everyone needs intervention for their emotional distress.

**Preferred medications.** The research participants were asked what their preferred medications were to treat anxiety and depression. The majority of the participants indicated that they typically use benzodiazepines for anxiety and Selective Serotonin Reuptake Inhibitors (SSRI’s) for depression.

*“For short term, benzodiazepines. For long term, usually the serotonin reuptake inhibitors.”*

*“Well, if its anxiety, it’s primarily benzodiazepines. If its depression, it’s typically SSRI’s, simply because I’m more familiar with them than I am with some of the newer antidepressants. Those are the things that I would use primarily.”*

*“With the advent of the SSRI’s now, they’ve been very helpful with very few, if any, side effects.”*

One participant commented that they prefer to use other medications.

*“I’m not afraid to use the old fashioned tricyclics in older people. I think in recent years they’ve been shown to not be as harmful as originally thought for other people and they often have a sedation effect that can be beneficial.”*

Additionally, one participant stated that while drug therapy is the preferred method, this participant also acknowledged they do not have much else to offer the patient.

*“I don’t have a lot of confidence in the overall effect of medications but we don’t have anything better, unfortunately.”*

The primary care providers that participated in this study indicated that medications are the preferred method of treatment for anxiety and depression and that they are mostly inclined to use benzodiazepines for the treatment of anxiety and SSRI’s for the treatment of depression. Several raised the concerns of long term use of benzodiazepines due to higher risks of side effects.

**Treatment response assessment.** The participants of this study were asked what they typically look for to determine if the prescribed treatment, whether medication or counseling, is working.

*“Usually interview with patient and family members. Readdressing the symptoms to see how well they are managed.”*

*“Of course [in] the nursing home I have follow up from the nurses.”*

*“Sometimes I can tell just by the way they are behaving, and ...fairly frequently it’s brought to my attention by a phone call from a family member or friend prior to the appointment.”*

*“Reversal of the symptoms, you know, turning around of the symptoms, better sleep patterns, less reactivity, you know, better train of thought.”*

All of the participants in this study indicated that they determine whether the prescribed treatment is working by their own observations and assessment of the problematic symptoms such as sleep, appetite, mood, etc. Furthermore, the research findings indicate that the patient’s self reports, family reports, and nursing home, hospice and home health staff updates are taken into consideration when assessing the response to pharmacologic or psychological interventions.

**Follow-up practices.** Ongoing assessments are an important aspect of determining if the patients are managing their emotional distress or whether the treatment is providing any relief. The participants of this study were asked to describe their process for following up with their patients in between clinic visits to see how they are managing. Most of the participants indicated

that they do not have any type of formal process. Two of the participants stated that they will call in very specific cases.

*“Sometimes I will call. Especially it’s common for me to have laboratory testing done and if it’s not an urgent thing I’ll wait a few days and then call and report the lab and see how they’ve responded to what we might be doing. It’s not something I do with everyone, it depends on the circumstance.”*

*“Once in a while, and not every time, I’ll call, you know, usually 3-4 days later. Patients that I potentially think may be at risk for being at risk. A phone call to see how they are.”*

Two of the participants stated that they do not initiate follow up with patients between visits but get calls from nursing home, hospice, or other medical staff who provide feedback on any intervention that had been started.

*“No formal mechanism unless they are involved in hospice or have other services or other home health.”*

*“Between office visits, no. Let me rephrase that. No for clinical patients. For nursing home patients the nurses call and provide feedback.”*

Two of the study participants indicated that they put the responsibility on the patient to contact the provider within a few weeks to let them know whether the intervention is working or not.

*“I think I’m pretty good about telling patients to call before the next appointment if things aren’t working. Or I’ll often tell them to call anyway to let me know if it’s helping.”*

*“I usually tell people most of the time to come back in a month if I start them on anything new. But usually I tell them to give me a call within 2-4 weeks. We do not make a call. I just have them do it and we’ll say if something changes or if something is worse, call us.”*

The findings from this study indicated that the majority of the participants usually do not initiate any follow-up with their patients on a regular or routine basis. On occasion when calling to update the patient on a lab result the provider will inquire about how the patient is doing with a new medication but usually it is left up to the patient to report any progress or problems to their doctor.

### **Use of Social Work and Mental Health Services**

One of the focuses of this study was to examine how primary care physicians utilized social work and mental health services. The participants were asked several questions about how they felt social work and mental health services could be of benefit to their patients with advanced diseases and whether they had a process for referrals. There was a significant amount of support for social work services and many of the participants actively use social work services that are currently available to their clinic patients.

*“ I think absolutely they can be of benefit because it often takes a great deal of time to elicit from the patient what the fear and anxieties are and try to come up with specific things that can help relieve those stresses and anxieties. It may be tension from family members. It may be financial stress. There can be many and varied reasons for this, so yes, I think social work and counseling services can be very helpful in identifying these and help them to be rectified.”*

*“My first thought is that yes, I think they could be of benefit. How? Probably kind of on the capacity of the last couple of things that we’ve just talked about. Providing that kind of extra support in between visits to the physician.”*

*“Social work, yes definitely would be beneficial. We’ve been asking administration to have a social worker here for the clinic and that would benefit getting in touch with patients, the family and getting some feedback because it’s the time thing. I think none of the providers have the time to keep calling people.”*

*“Yeah, I think helping coordinating follow up...Frequent follow ups, reconnecting, helping them get into counseling, assisting with that assessment of effectiveness.”*

Three of the participants of this study discussed their process of accessing the hospital based outpatient social work service for assistance with their patients in the clinic setting. This social worker is employed by the hospital but assists with outpatient needs.

*“Because with these social situations that you perceive, she is a savior in terms of finding the appropriate people to start dealing with these people in their homes so I don’t have to make 5 phone calls. I call or leave a message with [the hospital based outpatient social work service] and she gets it then. I’m very pleased with that.”*

*“I email [the hospital based outpatient social work service] about a patient and get her input.”*

Another three participants stated that while they support the use of therapy and counseling, they do not typically utilize ‘psychiatric’ support (psychiatrist involvement) unless the patient is having significant mental health issues that have failed previous treatment.

*“It’s unusual that I would ask for psychiatric help. It’s usually social workers or psychologists that can provide the benefit, but if somebody is really having difficulty with profound or psychotic depression then I would need help.”*

*“We’ve got a couple of them that have had some pretty significant psychiatric issues and we’ve had to get in the nursing homes here, we’ve had to get [psychiatric nurse practitioner] involved and in a couple of cases quite a few other people involved to handle it.”*

In contrast, one of the participants indicated a lack of knowledge about the education and training of social workers have or their level of comfort in dealing with emotional issues.

*“I think if the social worker had some training and expertise in dealing with mental health issues, it certainly could be of benefit to them. I’m not sure personally to what extent most social workers have training in that or to what extent most social workers feel comfortable in trying to address that issue.”*

In addition, another participant acknowledged that hospice is a very good resource for patients with emotional issues at end of life and indicated that a palliative care program would be very beneficial for these patients on a long term basis.

*“Without a doubt, hospice is a great resource for when they get to that point. It would be great if we had a palliative care for longer term patients along those same lines that could provide those services. That would be outstanding.”*

The results of this study indicate that these participants are fairly well informed about the benefits that social work and mental health services can offer their patients with anxiety and depression with advanced disease. They highlighted services such as coordination of care,

follow up calls and counseling as being most beneficial. Several of the participants frequently utilize services and advocate for the use of social work services. Even though the majority of participants were knowledgeable of the social work resources, it became apparent that a couple of the participants may not have enough information on the availability of such services for their patients indicating a need for more resource education. Further, a few participants did not know the extent to which social workers could provide mental health services, which might prevent referral to them for this purpose.

### **Barriers to Utilizing Social Work and Mental Health Services**

The participants of this study indicated that access to social work services is fairly good and readily available in most cases, however, access to mental health providers is a significant issue especially in rural areas. The participants of this study also discussed the difficult process of getting their patients referred to mental health clinics.

*“Now if I was relying on getting a person into our psychological or psychiatric services I would be disappointed.”*

*“We have a referral process in our office that’s often limited by staffing availability. And patients won’t necessarily participate in those activities.”*

*“The only problem would be the difficulty in getting mental health appointments. That’s the main issue.”*

*“It would be great if we had counselors in the building that we can say, hey, come on down I have someone for you to meet.”*



Limited availability of mental health providers, long waits for appointments, and complex referral processes contribute to the frustration that these study participants have in utilizing mental health services.

**Payment or insurance barriers.** Two of the research participants brought up the issue of insurance coverage or ability to pay for mental health services and how that poses as a barrier to utilizing some of these supportive programs.

*“Patients that don’t have insurance.”*

*“The only other concern would be of course payment. Depending on what kind of insurance patients have, they may not be able to afford the services. They may not be covered by whatever they have.”*

Research findings indicated that insurance coverage and associated expenses for mental health services play a significant role in whether patients will accept counseling and other mental health services.

**Stigma.** Only one of the research participants briefly addressed the issue of stigma and mental health and the role that stigma plays in a patient’s willingness to participate in counseling or receive formal mental health services.

*“I think there’s some stigmatism about not being able to manage those types of things.”*

Outside of this one comment, the issue of stigma was not brought up by any of the other participants in this study. It is well known that stigma regarding emotional or mental health problems is a major factor within our society and affects people’s willingness to receive

appropriate treatment and support. It could be that for rural areas, such as this site, that receiving mental health services is even more stigmatizing.

**Knowledge of resources.** One participant acknowledged that a barrier to utilizing social work and mental health services is their personal lack of knowledge on what is available for their patients.

*“I guess maybe my lack of knowing what’s available and how to, you know, what they do.”*

Understanding where the knowledge gap is on awareness of resources will help to determine future research and program development. Physicians and medical providers are often unaware of the skill set that social workers bring to their profession. This creates a barrier to using social work and mental health services.

**Patient’s receptiveness to treatment.** Several participants reported that even though they feel that formal mental health services and counseling would be very beneficial for their patients, the patient is often not receptive or amenable to following through with appointments or referrals that are made.

*“I think patients are more receptive to medications than counseling. ...I notice that I’ll make, sometimes, I don’t even know what to say how many, but you know there seems to be quite a few that when I do refer, they don’t keep the appointment.”*

*“There’s a lot of cases where a lot of people don’t comply and they don’t go and you can see that it doesn’t help to talk about something that they’re not willing to do anything about.”*

One participant indicated that the majority of their patients who are referred to mental health programs do follow through and are receptive to receive counseling. However, it was noted that in the majority of cases there are significant barriers to accessing formal mental health services. According to this study the barriers to utilizing social work and mental health services vary. The participants highlighted the lack of appropriately trained staff, insurance coverage, lack of knowledge of available services, and patient receptiveness to psychological therapy as the primary reasons for not accessing these types of support services.

As a result of noncompliance, lack of follow through, and the stigma related to formal mental health referrals, several research participants discussed their method of providing support to those patients who refuse to go to formal counseling.

*“I’m usually pretty straight forward and acknowledge that what they’re feeling and going through, that it’s very difficult, it’s very difficult and that it’s not unusual for people to feel more down or anxious with all of the changes that their experiencing in their lives and things that they’re going through right now. So I acknowledge that it can be a normal process and you know it’s often times people will then acknowledge that yeah, they are feeling some of that.”*

*“You can see that certain patients who really need this addressed and it’s gonna be beneficial even if you just spend a short period of time with them and again helping them out and again, I think that a lot of times...they’re receptive to what little bit of help the physician can be.”*

*“Try to have some impact, some beneficial impact on the patient’s life and experiences. Not in this case their longevity but in their enjoyment of time that they have.”*

*“They feel appreciative that you understand that they are anxious about this.”*

These participants indicated that spending time listening to their patients' stories while acknowledging and normalizing their feelings is typically provided in lieu of formal counseling services.

### **Time Constraints**

The participants of this study were asked about what their disincentives were in addressing anxiety and depression in patients who have advanced diseases. The overwhelming majority of this group indicated that time constraints was the largest barrier to meeting their patients' emotional needs.

*“The disincentives are definitely the time crunch in the office and it is often difficult to make time to do an adequate assessment of these things.”*

*“Well, it's always a long visit because it usually takes time to pull those things out and figure out and establish a rapport with the patient regarding depression. That has a whole different attitude toward it ...than regular disease when you can put your finger on it and say here's the problem. So it does take a lot of time.”*

*“I think that time is the biggest constraint because I think it's very time consuming to address these kind of issues.”*

*“It is the time factor and trying to arrange a few things for the person who needs a lot of help. So really a 15 minute office visit can turn into an hour which can really put me back in doing or seeing other patients.”*

Two of the participants discussed the fact that when they try to address the emotional needs of patients in a clinic setting, often times the family members or caregivers who are

present will bring up their own emotional issues and stresses sometimes related to the patient's illness and sometimes not. These study participants discussed how these additional needs change the dynamic of the office visit and can take a lot of extra time that wasn't anticipated.

*"All of a sudden you're assessing the patient for that [anxiety and depression] and then you know the wife over here falls apart or the sister or the daughter or the son. You know they're coming apart because of caregiver fatigue or they've got some other issues that again one of these unresolved issues that happen in families."*

*"Frequently I say, please on your next visit in a few weeks, bring in your son or your daughter or a specific son or daughter, whom I probably know, so we can talk about this. I do not want a hysterical son or daughter. I want somebody who can understand and accept what we're going about here."*

These participants brought up the issue that having family present for discussion about the patient's medical and emotional status for the most part is beneficial, however, at times the family's emotional or medical issues can dominate an office visit and take time away from meeting that patient's needs as well as the other patients who are waiting for their appointments.

Furthermore, the participants were asked several questions about how much time they spent in an average office visit addressing anxiety and depression in patients who have advanced disease. These respondents reported:

*"Not a great deal, simply because the office visits tend to be fairly brief, 15-20 minutes and so at the most 10-15 minutes get spent concerning that issue."*

*“Well, obviously variable from patient to patient. I normally ask about it, sometime if it doesn’t seem to be an issue, that’s probably all that gets addressed at that point. If it’s an issue for the patient and frequently that’s a primary reason for the visit and pain issues always bring that up because that obviously causes depression all by itself.”*

*“That depends entirely upon the patient’s acceptance of what’s happening to him or her. Sometimes it’s just not necessary to spend time with this at all but other times it can be quite time consuming. And sometimes a half an hour can go by and we try to help the patient and help the family with the issues.”*

*“Depends on the complexities. If somebody’s diagnosed with a recent cancer and then there’s more time involved, sometimes 45 minutes. But if it’s a person I know and has a chronic disease for a while and something’s suddenly changed, it may be 10-15 minutes.”*

*“If there’s a significant component of anxiety or depression, I think it ends up being, many times, the major focus of the encounter. Most of the time, the other palliative issues that need to be met are more readily or more easily addressed. If they need more pain medication, that can be addressed pretty readily and easily. If they need more supplemental oxygen or something, that can be addressed pretty easily.”*

*“You have to take care of the anxiety and depression and fear but you have to be careful we don’t overlook other medical issues...that’s just part of practice.”*

Each of the participants indicated that while they do usually spend some time during the office visit assessing for anxiety or depression, the amount of time and the focus of the visit will depend upon the patient’s needs. The assessment may be very brief and a non-issue for the patient and at other times the emotional issues may dominate the entire office visit. Three of the

nine participants also acknowledged the role of unmet or uncontrolled medical symptoms in the development or worsening of emotional issues.

**Schedule implications.** All of the participants of this study talked about wanting to do the right thing for their patient and will take the extra time that is needed to help the patient and/or family deal with the emotional factors that arise from having a serious medical disease. These participants indicated that organizational pressure for productivity quotas were not a factor in their medical practice and that they take the time that is needed; however, there is personal pressure and stress that results because they get behind in their schedule which impacts other patients.

*“You know I don’t have any concerns about that, well, I guess it’s not so much productivity, it’s staying on schedule. You know you get involved in these things, you know, taking a step back and taking a deep breath and then digging into it and understanding the next patient’s gotta wait a half an hour because that’s what it will take. And just being aware of that and resigning yourself to it and pressing on. That’s probably the biggest issue, as far as being productive. I think it’s more of a schedule than anything else.”*

*“It’s just when you get to do what you need to do for the patient you basically end up putting yourself back and the next patient you’ll be seeing a half hour later.”*

The majority of these study participants indicated that productivity was not a significant driver in their medical practice but stressed that tending to the needs of all of their patients was very important. They reported that they will do what they can in the office visit to meet both the medical and emotional needs of the patient but they all indicated they feel internal pressure to

keep to their schedules as much as possible so other patient's are not waiting too long or that they are getting too far behind in their schedules.

### **Suggestions for Improving Medical Practice Regarding Anxiety and Depression in Patients with Advanced Diseases**

The participants in this study were asked a question about their ideas of what would be helpful to their practice in assisting patients with anxiety and depression. There were a variety of suggestions that were discussed such as having specialized staff available in their clinic; education; time and improvements in relationships with other departments/programs.

**Specialized staffing availability.** The majority of the study participants suggested improving the availability of social work and mental health services in the clinic would be beneficial in meeting the emotional needs of their patients. When the participants were asked, "What do you feel would be helpful to your practice in assisting these patients?" these participants stated:

*"I think the availability of more counseling and social work services to do more screening and evaluations."*

*"I think more availability of providers to help address that with counseling or better availability. I think there's still a problem with availability of people capable of doing a good job with that."*

*"The resources that I need, especially with [palliative care specialist] here and the hospital work, [palliative care specialist] are always very helpful and have eased my workload."*



*Having people of equal caliber working in the office would probably be the biggest benefit that I could get.”*

*“The idea that you mentioned about having social services that are focusing on anxiety and depression, having something like that available to help with that would be reasonable or having people aware of it within the social working area would be reasonable. Having somebody that can help the family with that, you know, implement some of those things, assessment and awareness with the patient in treatment. You know, where you could pick up the phone calls, if hospice isn’t involved, help with that whole issue of follow up. Because I think these folks typically require closer follow up or may be less inclined to call and check in saying it’s not working or things are now starting to fall apart despite what you’re doing, it’s getting worse ...and so I think that idea of closer follow up would make a huge difference. You know, more frequent follow up.”*

*“I think it might help if we just had a nurse in the area that would be accessible to us that would be specifically trained in this area that could come in and spend some time with the patient. That would be very beneficial.”*

Seven of the nine participants reported that having specially trained staff in their clinic who are readily available and accessible to meet with patients and families during the office visit to address the issues of anxiety, depression, fear, and preparation for end of life would be very beneficial to their medical practices.

**Education.** One participant stated that they would like more training.

*“I need a course or something in knowing how to counsel or what’s the right thing to say and do...I feel very helpless and lost on what, how to handle it.”*

Having additional training on what is the best way to handle a one-on-one conversation with a patient in regards to their anxiety, depression, fears, and other related emotional distress was suggested by this participant.

**Time factor.** One participant discussed issues of productivity and time constraints as factors in their ability to provide adequate attention to a patient's emotional distress.

*"I think in an ideal world, taking away the issues of productivity...or time constraints so I didn't feel like I had to have those issues in the back of my mind, but I don't see that happening."*

Time factors and the need to have a set schedule can hinder the medical provider's ability to address anxiety and depression in patients who have advanced disease.

**Relationships with other departments/programs.** Three of the participants brought up the idea that relationships and communication between their clinic and other departments and programs may help improve their ability to meet the emotional needs of their patients.

*"I think it would be helpful to be able to get a little better...connections with mental health. I think so far the social work situation has worked out well."*

*"We've all gotten used to using hospice care here but I wish hospice was a bit more responsive...I wish we could integrate with the hospice people better that we currently do. I don't propose that I know how we do that. You know, they take over and then we don't see the patient the last week, or two or three, of their life. It would be nice to integrate that somewhat better."*

*"I don't think that home health itself can care for anything. They usually can manage their medication, go there once or twice a week, but people need a lot more help."*

While these providers are willing to work with mental health, hospice and home health programs, they indicated a desire to have a more integrated approach and to be able to remain actively involved in their patient's care throughout the disease and dying process.

### **Patient Centered Home Medical Model**

One of the study participants commented on the Patient Centered Medical Home model that is being piloted within the clinic system and stated that they are hopeful that through the implementation of this model that better follow-up can take place through the use of other medical team members.

*“We’re hoping to [have a process for following up with patients] do that with what’s called the medical home model which is instituted now in [an associated clinic] and I think we’re gonna try to implement it either later this year or next year because right now there’s way too much to do that I wouldn’t have time to do that but obviously it’s a necessary thing to do and maybe overall it will decrease the costs of medical care.”*

This participant has been following the progress of the Patient Centered Medical Home model pilot in an associated clinic and acknowledged that by having a social work component in this integrated model of care would provide much needed services to the patients seen in their clinic. Many of the comments made by these study participants indicate that they would support an integrated medical model that utilized the use of social workers and mental health providers.

### **Findings Summary**

The participants had reported having little to no formal education on anxiety and depression in general, let alone in patients with advanced disease. However, each of these study participants have engaged in some type of ongoing education and have some exposure to this

topic through CME's, conferences and professional journal articles. One participant reported a need to have more specific training to help them feel more comfortable counseling patients on a one-to-one basis.

The findings in this research indicate that the majority of participants report that 100% of their patients with advanced disease experience some level of anxiety and depression, however that not all of their distress is significant to warrant formal pharmacological or psychological interventions. This study raised a question for the researcher there may be more of an issue of therapeutic nihilism than the research participants may have identified. The expectation that patients who have advanced and terminal illnesses should have anxiety and depression may contribute to the way that these primary care providers address or not address psychological distress.

Only a couple of the study participants used any formal assessment or screening tools, and in most cases used the tools only for screening serious mental illnesses. The data found that the majority of primary care providers rely on their clinical observation and intuition along with patient self-reports, family reports and updates from health care professionals in nursing homes, hospice and home health services.

Having to have set schedules and tend to high patient caseloads, there is limited time to address emotional issues or psychological distress. The participants of this study reported that they will tend to the emotional needs of their patients but feel internal pressure knowing that their other patients are waiting and they are getting behind in their schedules. None of the participants in this study reported that clinic structure or organizational productivity quotas were a factor in how they managed their clinic practice.

## **Discussion**

This research study set out to examine how primary care providers assess and identify anxiety and depression in their patients with advanced disease including what treatment methods they use in this patient population, as well as their usage of social work or mental health services. There were many themes that were found in the data analysis that support previous research and other themes that appear to be original with this research.

### **Prevalence of Anxiety and Depression in Palliative Care Patients**

The findings of this study did not include a formal assessment of participants' patient caseload to determine prevalence, however, the research participants were asked to provide an estimate of the percentage of their patients who experience anxiety and depression at the end of life. Eight of nine participants stated that they believed the number of their patients who experience anxiety and depression in the advanced stages of illness ranged from 50% to 80%. One participant reported that approximately 25% of their patients at end of life experienced significant emotional distress.

The literature discussed the difficulty that primary care providers have in determining the prevalence of anxiety and depression in patients who have advanced disease. Furthermore, the research indicated that these emotional disturbances are frequently under-recognized in the medical setting and is often affected by the patient's symptom severity, duration, and co-morbidities (Hotopf, et al., 2002). It has been reported that depression is the most commonly experienced mental health illness and is often easily overlooked (Hotopf, et al., 2002). Moreover, the research suggested that having a terminal illness increased the risk of developing anxiety and depression, stressing however, that it is not a normal and expected part of the dying process (Periyakoil & Hallenbeck, 2002; Lyness, 2007). The participants in this study reported

that they believe the majority of their patients experience some level of anxiety and depression, although they emphasized that not all of their patients want or need any formal interventions.

### **Risk Factors for Developing Anxiety and Depression**

The findings from the current study correspond with previous research regarding the impact of uncontrolled symptoms such as the presence of pain and other uncontrolled symptoms (Zeiss, et al., 1996; Block, 2000) and social isolation in the development or exacerbation of anxiety and depression in patients who have advanced disease. Patients who experience increased social isolation have been found to have higher levels of anxiety and depression (Zeiss, et al., 1996; Reeve, et al., 2008; Akechi, et al., 2004) or changes in key support relationships (Lloyd-Williams & Friedman, 2001; Hill, et al., 2008). Furthermore, participants in this study reported that patients who have good family support tend to have better coping mechanisms and do better than patients who are dealing with a serious illness on their own.

Interestingly, while researchers have found that inability to perform daily living tasks was associated with the development of depression (Tsunoda, et al., 2005; Zeiss, et al., 1996), the current respondents did not mention this. Another difference between previous research and this study was the role of severe fatigue (Akechi, et al., 2004; Tsunoda, et al., 2005) as a risk factor for developing anxiety and depression. None of the participants in this study addressed fatigue as a factor for anxiety and depression.

Furthermore, Primary care providers should be aware of these risk factors for developing significant anxiety and depression in patients who have been diagnosed with incurable, progressive illnesses. Initial and ongoing, thorough assessments are critical to address not only the physical illness and its associated symptoms and side effects but the psychological distress that often accompanies serious illness. Early diagnosis and implementation of the appropriate

treatment may positively influence the patient's overall quality of life as well as physical illness (Durkin, et al., 2003).

### **Screening for Anxiety and Depression in Primary Care**

There are mixed findings in the current study with regard to the use of standardized assessment instruments. Two-thirds of the participants in this study indicated that they do not use any formal or standardized assessment tools. They reported that they use their intuition and clinical observations as well as patient, family and other staff reporting to identify signs and symptoms of anxiety and depression. In this case, physician intuition may be more than just a "gut feeling" but includes patient history gathered over time and through the relationship the provider has had with the patient. Many of the providers in this study have been caring for their patients for many years and have developed an understanding and knowledge of the patient's physical and emotional baseline. Some of the providers stated that they ask particular questions, which are based on how well they know the patient as well as their intuition. This practice coincides with Hill et al's (2008) recommendation to ask a few screening questions to determine whether a more thorough assessment is warranted. Periyakoil & Hallenbeck, (2002) suggested that using a two question screening tool is the best option for palliative patients. Questions such as "Are you depressed?" or "Have you lost interest in activities or things that you would normally enjoy?" have been proven to be an appropriate tool for palliative care patients (Payne, et al., 2007; Breitbart, et al., 2009) and help to determine whether a more detailed assessment for anxiety and depression is necessary.

Many of these participants have followed their patients for many years and have gotten to know them very well over time, including their coping mechanisms and support systems. The participants in this study reported belief that almost all of their patients experience some level of

anxiety and depression when facing end of life, but that not all patients need or want any formal psychological or pharmacological intervention. Screening for anxiety and depression in patients who have advanced disease is imperative not just at the time of initial diagnosis but throughout the disease trajectory to determine when pharmacological or psychological intervention may be needed (Mystakidou, et al., 2005; Hill, et al., 2008; Culpepper, et al., 2008). According to this study, the participants stated that some of their patients have accepted their terminal status and have prepared for end of life much better than others. Research has indicated that patients may have strong coping skills to deal with certain parts of the illness better than others (Hoffman & Weiner, 2007; Hill, et al., 2008) and their ability to cope and adapt to disease changes varies according to the patient's age, life experiences, social support, attitudes and cultural values (Germain & Gitterman, 1980). Due to the complexities of identifying anxiety and depression within the context of advanced medical disease, it has been recommended that physicians use simple screening questions to identify patients with psychological distress so that they may benefit from a more detailed evaluation (Hill, et al., 2008).

### **Barriers to Identifying Anxiety and Depression in Patients with Advanced Disease**

There are a number of other barriers that also affect the physician's ability to assess for, identify and adequately treat anxiety and depression in palliative patients.

**Physician factors.** While there is a significant amount of evidence that suggests many primary care providers are affected by their own biases - nihilism (Block, 2000) and transference phenomenon (Zinn, 1990) which impacts their ability or willingness to explore feelings of anxiety and depression in palliative patients - none of the participants in this study expressed any of these physician bias issues, nihilism or transference phenomenon. This does not necessarily mean that transference doesn't play a role. It can be difficult to get people to talk about so



personal in a brief interview. While the participants were not asked any direct questions regarding these issues, they were asked to identify what their incentives and disincentives were in addressing anxiety and depression in patients with advanced disease. Many of the participants of this study brought up issues of time constraints and lack of knowledge about these issues; none mentioned emotional discomfort in broaching the subject of depression and anxiety. This may be because providers do not feel discomfort, but it also could be because providers are worried about it and embarrassed to mention it. If primary care providers are emotionally uncomfortable dealing with anxiety, depression and preparing patients for end of life, patients who are experiencing these psychological issues may not get their psychological needs met, thus resulting in poorer quality of life, increased grief issues and possible requests for hastened death. The belief that anxiety and depression is normal and expected at end of life may hinder the patient's ability to work through anticipatory grief issues, prepare for dying and have closure with family and friends (Block, 2000; Pessin, et al., 2002).

Furthermore there may be issues of compassion fatigue that play a role in the provider's ability to address issues of anxiety and depression which may benefit from further exploration. If a provider is experiencing compassion fatigue, they may not have the emotional ability or energy to explore the patient's psychological distress for fear of opening "pandora's box" (Radey & Figley, 2007).

**Lack of standardized diagnostic criteria.** The participants of this study were asked what symptoms they look for to identify signs of anxiety and depression in patients with advanced disease. The majority of these participants, consistent with previous research, rely on somatic complaints, changes in sleep patterns, mood swings, changes in thought processes, and similar symptoms, to identify anxiety and depression. Several participants also brought up

additional triggers such as pain and other physical symptoms that appear to be disproportionate to the patient's medical disease and behaviors that may manifest as a result of untreated emotional distress. Symptoms such as fatigue and anhedonia (loss of interest or pleasure in activities) (Robinson & Crawford, 2005; Pessin, et al., 2002; Wasteson, et al., 2009), weight loss and insomnia (hallmark symptoms experienced by cancer patients) (Lawrie, et al., 2004; Hoffman & Weiner, 2007) or anxiety which can mimic physical illness in patients with respiratory distress such as COPD (Kelly, et al., 2006) all create challenges for the physician to determine whether the patient is experiencing anxiety and/or depression or whether these symptoms are a direct result of the underlying medical disease. A number of researchers have found that the lack of standardized diagnostic criteria for patients who have advanced disease contributes to the primary care provider's inability to adequately assess for anxiety and depression in palliative care patients (Eisenberg, 1992; Payne, et al., 2007; Roundy, et al., 2005).

Research has shown that patients who have advanced disease do not exhibit anxiety and depression in the same way as the general public and that traditional diagnostic measures such as the HADS (McCoubrie & Davies, 2006; Miller, et al., 2006) and Beck Depression Scale (Pessin, et al., 2002) are not adequate for identifying psychological distress in this patient population. Patients with advanced disease are particularly challenging for physicians to identify anxiety and depression due to the somatic complaints that often occur as a result of the disease trajectory (Miller, et al., 2006; Lawrie, et al., 2004), therefore it is important for all patients with advanced disease to have a thorough diagnostic assessment. As suggested in this study as well as previous research, asking a patient a few specific questions, such as the two question screening tool about depression and anxiety (Periyakoil & Hallenbeck, 2002) may be effective screening to determine who then needs a more formal assessment. It is apparent that further education is needed for

primary care providers to understand the impact of the terminal disease trajectory on the possible development of depression and anxiety, as well as treatment side effects and their relationship with somatic complaints when considering a diagnosis of anxiety and/or depression.

**Patient related factors.** The findings of this research are mixed when compared to previous research regarding patient related barriers. The participants in this study indicated that they rely on patient self reporting on symptoms of anxiety and depression whereas previous research stressed that patient non-disclosure is a prime barrier to primary care providers identifying symptoms of psychological distress. A couple of the participants did indicate that sometimes patients do not recognize that they are anxious or depressed and that the emotional distress manifests in behaviors.

Patient non-disclosure (Lawrie, et al., 2004; Lloyd-Williams, 2001) is a key factor that impacts the primary care provider's ability to assess and treat emotional distress such as anxiety and depression. Some patients believe that their emotional reactions are a normal and expected reaction to their terminal status (Block, 2000; Pessin, et al., 2002) and neglect to raise these issues with their provider. Moreover, many patients do not recognize that they are experiencing anxiety and depression, attributing their symptoms to their medical disease, medication or treatment side effects (Hotopf, et al., 2002) and at times underestimate the level of their own distress (Lloyd-Williams, 2003; Hoffman & Weiner, 2007). Because patients do not readily volunteer these issues, it is essential for the health care team to take the time to evaluate for signs of anxiety and depression at routine appointments throughout the disease trajectory (Durkin, et al., 2003; Enguidanos, et al., 2005).

**Stigma.** In this study, only one of the participants referred to the issue of stigma and the role that it plays in whether a patient would consider formal counseling. There have been

previous studies regarding concerns about stigmatizing the patient with a mental health diagnosis (Hoffman & Weiner, 2007; Block, 2000; McQuaid, et al., 1999). Outside of the comment made by one participant, neither the issue of physician bias nor stigmatization was addressed in this study. This researcher questions the role of physician bias (positive or negative) and how it may impact the patient's acceptance or declination of counseling services due to stigmatization. Further research may be needed to further explore regarding the role of physician's bias and the effects of diagnosing a patient with anxiety and depression and the relationship of these issues at end of life.

It may be important to take into consideration the role of culture and the fact that this study took place in a rural community where many people tend to be very private and stoic about their emotional well-being. The primary care providers may be making an assumption that they don't think their patient would want counseling at the end of life, however, it may not only be physician bias or a particular patient, it could be that it is seen as a sign of dependence or self-insufficiency. It may be worth exploring how patients are approached and treated in relation to community and cultural values to determine the role of bias by both physician and patient.

### **Preferred Treatment Methods**

The findings of the current study are mixed when compared to previous research. The current study supported the literature in regard to the use of medication intervention. The majority of the participants reported that they rely on the SSRI's for both anxiety and depression due to the low risk of complicating side effects. However, according to the research, even when patients are identified as having anxiety and depression, they are often undertreated (Robinson & Crawford, 2005; Pessin, et al., 2002; Block, 2000). One participant reported a preference for the tricyclic antidepressants and several other participants expressed concerns about long term use of

the benzodiazepines. One participant acknowledged that there are limitations in the treatments that we currently have to offer for this patient population. None of the participants in the current study identified that they use psychostimulants for patients at end of life. The participants in this study reported that they tend to use a few select medications that they are most comfortable with. According to the research, when pharmacological interventions are considered, SSRI's have been determined to be the drug of choice for treatment of depression in patients with advanced disease because they have a relatively quick response time and fewer side effects than the tricyclic antidepressants (Periyakoil & Hallenbeck, 2002; Lloyd-Williams, 2003; Hotopf, et al., 2002). Furthermore, the majority of the participants in this study, consistent with the research, indicated that the ideal treatment includes pharmacology in addition to psychotherapy, but reported many patients refuse counseling, therefore forcing the physician to rely on medication interventions alone. Research has indicated that providing pharmacology, psychotherapy and patient education are the most effective treatment strategies (Lloyd-Williams, 2001; Durkin, et al., 2003; Periyakoil & Hallenbeck, 2002). Evidence suggests that patients with advanced disease are less likely to go to a mental health provider, preferring to go to their primary medical provider to care for their emotional needs (Lawrie, et al., 2004).

The participants in this study stated that they try to individualize the treatment interventions to their patient's needs based on the patient's willingness to participate in pharmacological or psychological treatments; this individualization includes the consideration of the provider-patient relationship, family and community support, and overall coping mechanisms. However, many of the participants noted a lack of comfort in dealing with these issues in part due to lack of education and training. Due to these realities, Hoffman and Weiner

(2007) recommended that physicians develop good working relationships with mental health providers.

Historically, psychiatrists were the providers in control of a patient's overall mental health care including prescribing medication and psychotherapy, while clinical social workers performed psychosocial assessments, held family meetings and coordinated discharge arrangements (Cohen, 2003). However this traditional approach to mental health care has been changing and according to Cohen (2003), clinical social workers are now performing the majority of psychotherapeutic counseling, while the psychiatrist's role and scope has narrowed to medication management and complex care situations. A couple of the participants in this study stated that they will refer to psychiatry for difficult cases for guidance with medication management.

**Ongoing assessments.** The findings of the current research indicated that primary care providers may routinely reassess issues in the clinic setting, but these participants do not usually make any attempts to touch base with the patient in between clinic appointments. Research has indicated that the palliative patient's psychological well being is vital for maintaining good quality of life and stressed the importance of addressing psychological distress as a crucial part of medical care (Tsunodo, et al., 2005). Several of the participants in this research reported that they did not believe that their process for evaluating or addressing anxiety and depression in patients with advanced disease changed as the patient's disease progressed. Some of the participants stated that their approach may vary depending on the patient's needs, fears and anxieties. The participants in this study stressed that the majority of their patients are people that they have known for a long time and that they take their cues from the patient on how those issues are addressed. There is evidence that early identification (Culpepper, et al., 2008) and

frequent reassessment (Hoffman & Weiner, 2007; Block, 2001; Wasteson, et al., 2009) of psychological distress is necessary to reduce symptoms of anxiety and depression as well as improve the patient's overall quality of life (Durkin, et al., 2003) as the patient's emotional well-being will fluctuate throughout the disease process (Block, 2001). Several participants stated that often times the focus of the clinic visit changes from the long term management of the illness to more short term management due to the limited life expectancy.

Further research would be necessary to determine how well patients follow up with their primary care provider regarding these emotional issues and whether the patients feel well supported by their primary care provider. It is likely that due to sporadic follow up visits combined with the physician, patient and disease related barriers that palliative patients emotional needs are not well managed thus affecting overall quality of life.

### **Benefits of Utilizing Social Work and Mental Health Services**

The findings of the current study support previous research regarding the benefits of using of social work and mental health services. However, contrary to previous research, the participants of this study expressed a significant amount of support for social work services and many of them currently utilize the social work services that are available to their clinic patients even though the social worker is not a defined member of the clinic healthcare team. The participants reported that they access social work services to help elicit information from the patient regarding their fears and anxieties such as family tension or financial stress. The participants stated that the social workers have been able to come up with specific resources and community supports that have helped relieve the patient's stresses and anxieties. Some participants reported that having social workers contact their patients in between office visits to provide additional support, obtaining feedback on treatment response, coordinating follow up

and community resources have been particularly beneficial to the patient, family and primary care provider. Having social workers located directly in the clinic and readily accessible to address patient or family needs help to normalize the use of social work services and may reduce any potential related stigma.

While the findings of the current study indicate support for social work services, several barriers were identified in being able to access mental health services. The participants expressed frustration with the accessibility of mental health providers due to limited mental health provider staff availability, long waits for appointments, and complex referral processes. Additional barriers that were reported include the lack of insurance or financial assistance to cover the costs of professional counseling. Also, as previously mentioned, the stigmatization associated with having a mental health diagnosis affects a patient's willingness to participate in counseling or receive formal mental health services. Moreover, these participants reported that patients are often not receptive or amenable to following through with appointments or referrals that are made.

Furthermore, there was one finding that supports previous research which is evidence that most primary care providers are unaware of the education, training and skill sets that social workers can bring to the primary care clinic practice. This provides confirmation that education should be directed to primary care providers regarding the ways in which social workers can provide support and assistance (Kitchen & Brook, 2005; Zimmerman & Dabelko, 2007). This education can be very beneficial in developing collaborations between primary care providers and social workers. Research suggests that collaboration with interdisciplinary and multidisciplinary team members provide early intervention and variable treatment plans that



improve continuity of care and ultimately strengthen the patient-physician relationship (Lesser, 2000; Zimmerman & Dabelko, 2007).

### **Patient Centered Home Medical Model of Care**

This study failed to support previous research on the impact of the patient centered home medical model of care, primarily because there were no participants currently involved in a patient centered home medical model clinic. The clinic system in which the current study was conducted is currently piloting a patient centered home medical model in one of their clinics; however, there were no primary care providers from this pilot site that volunteered to participate in this research. It would have been quite interesting to see if there were any differences in the interview responses between the primary care providers at the two clinics. The clinic that is piloting the patient centered home medical model has employed both nurse case managers as well as behavioral health specialists, one of which is a social worker, who assist the medical provider in managing both preventative care and chronic disease management. The providers who participated in this study are very interested in the outcome of the pilot study and expressed interest in the development of this model of care in their clinic; many of these providers access hospital medical social workers to assist with their clinic patients' psychosocial needs because they do not have a social worker within the clinic. These study participants indicated that they would support an integrated medical model that utilized the use of social workers and mental health providers.

The collaborative models of care, such as the patient centered home medical model, that integrate social work services emphasize that the focus of care is on both the medical disease and psychological issues that may be contributing or resulting factors of the medical disease (Lesser, 2000). This team approach increases the number of contact points between the patient and the

health care team (Rosenthal, 2008). Furthermore, having a social worker on the team provides easy accessibility to the patient, decreases the stigma of social service involvement, and increases the likelihood that the patient will follow through with social work referrals (Lesser, 2000). Moreover, the research has suggested that outpatient follow up care was directly impacted by the presence of a social worker on the team.

### **Education**

The participants in this study were asked several questions concerning their formal and informal training on the identification and treatment of anxiety and depression in patients with advanced disease. The majority of the participants reported that they had not received any formal training, even during their residency, regarding identification of anxiety and depression. One of the nine participants indicated that their residency program included rotations in geriatrics, cancer and end stage diseases. All of the participants stated that they have participated in CME workshops, read current professional journals, participated in online education and attended conferences; however, none of these training opportunities specifically addressed anxiety and depression specifically in advanced disease. One participant reported a desire for more specific education on how to counsel patients in order to better manage their emotional distress, especially for those patients who refuse to go to a professional counselor.

The literature discussed the issue of insufficient education regarding identification and treatment of psychiatric illnesses (Hoffman & Weiner, 2007; Block, 2000; McQuaid, et al., 1999). Anxiety and depression are two of the most common psychological issues that arise in the general population and in individuals with advanced disease (Lawrie, et al., 2004; Lloyd-Williams, 2001; Pessin, et al., 2002). It is imperative that primary care providers have sufficient education regarding the impact of advanced disease and the development of anxiety and

depression. Providing education to the primary care providers will increase their ability to identify the risk factors for anxiety and depression in patients with advanced diseases, thereby improving patients' quality of life, especially those who have shorter life expectancies.

### **Time Constraints**

The findings of this study correlate with previous research regarding time constraints and the impact on the primary care provider's ability to thoroughly assess and treat the psychological distress of their patients with advanced disease. The findings of this study indicated that the providers will spend the time needed to address psychological distress, but they often will fall behind in their appointments creating internal pressure to stick to their schedules and frustration for patients who are kept waiting. The participants of this study stated that they almost always inquire how the patient is managing with their illness. For some patients, who are coping well, that is all the time that is spent on the issue of anxiety or depression. For those patients who are not managing their anxiety, depression or fears, these issues can dominate the entire office visit or longer, leaving little time to address any physical symptoms such as pain, dyspnea or other issues. The participants in this study acknowledged that pain and other symptoms that are uncontrolled can contribute to the level of anxiety and depression that a patient with advanced disease may experience.

It has been well documented that addressing emotional issues such as anxiety and depression can take a lot of time, frequently, much more time than is allotted in an average office visit (Lesser, 2000; Eisenberg, 1992). With an average office visit ranging between 6 and 15 minutes, there is not enough time to explore psychological concerns (Eisenberg, 1992) and there is a struggle to manage the emotional needs of the patient in such as limited clinic appointment while also addressing any of the patient's medical symptoms such as dyspnea or pain.

Another factor that the participants in the current study brought up was the issue of family or caregiver burden and how that can impact an office visit. While patients are encouraged to bring a family member to the appointment, sometimes these family members are feeling overwhelmed by the patient's advanced disease care needs and may fall apart during the office visit which takes time away from the patient. This complication was not addressed very much in the research and may benefit from future exploration as a factor that gets in the way of addressing anxiety and depression in patients with advanced disease.

**Productivity quotas.** The participants in the current study were asked about the role of organizational or clinic pressures to maintain productivity quotas and their ability to meet the emotional needs of their palliative patients. In this study, all of the participants talked about their personal incentives to provide the best care possible for their patients, including taking the time necessary to address anxiety, depression and fears expressed by their patients. All nine of the participants indicated that organizational pressure for productivity quotas was not a factor in their medical practice and that they take the time that is needed. This finding does not correspond with previous research. However, several of the participants acknowledged that this may be more of an issue for younger, newer physicians who have large debts and other financial incentives to maintain productivity quotas. Eisenberg (1992) discussed how the structure of the current health care system pressures the clinician to be productive regarding the number of patients that are seen in a day, as well as how they are reimbursed for services provided. Future research should consider how experience and point in career may affect appropriate assessment and treatment of depression and anxiety in patients.

**Office visit outcomes.** This study examined how addressing anxiety and depression during the office visit affected the overall outcome of the visit. The majority of the participants

indicated that usually the outcome was positive for the patient, family and provider stating that creating awareness of any emotional distress helps not only the patient but the family. Previous research stated that often patients may be reluctant to raise these concerns for fear that they are “going crazy” and fear the associated stigma (Durkin, et al., 2003; Block, 2000). It has been suggested that since patients do not readily volunteer these issues, it is imperative for the health care team to take the time to evaluate for signs of anxiety and depression at routine appointments throughout the disease trajectory (Durkin, et al., 2003; Enguidanos, et al., 2005). Participants in the study stated that their patients have expressed appreciation that the primary care provider acknowledged and addressed these emotional issues.

### **Identification of Palliative Patients**

A surprise finding in this study was the conclusion that several participants did not recognize that they see palliative care patients in their clinic practice. All of the participants of this study provide primary medical care in the form of Family Practice and Internal Medicine. All of the participants see patients in their clinic. The majority of participants also follow patients at area nursing homes as well as patients in hospice and home health care. According to the researchers for the National Consensus Project (2009), palliative patients include patients with advanced diseases illnesses as cancer, chronic obstructive pulmonary disease (COPD), heart disease, neurological diseases, kidney failure and dementia, although this is not an exhaustive list. Palliative patients have illnesses that are not curable but in many cases they are pursuing some type of life prolonging treatment while they are nearing the end of their life.

It should be noted that several participants in this study stated that the only palliative patients they follow are the ones at the nursing home and in hospice care. These were also the situations in which the participants stated they rely on the professional observation and judgment

of the nursing staff at the nursing homes and hospice programs to identify anxiety and depression in these patients. The remaining participants in the study acknowledged that they have a varied patient caseload including patients who have chronic illnesses; many of them are elderly with multiple medical problems. One possibility for this discrepancy may be varied perceptions and definitions of what constitutes “palliative care,” thus warranting education for primary care providers on the definition of palliative care and what types of patients would be considered to be palliative patients.

### **Implications for Social Work Practice, Policy and/or Research**

This study reveals that there are several implications for social work practice and policy. The trend in healthcare is to move toward an integrative and collaborative approach to care that utilizes social work services in a more comprehensive manner than has been available in the past. As noted previously, health care is the single largest field of practice for social workers (Holosko & Taylor, 1994). Therefore, the movement toward a collaborative medical care will place social workers in a strong position to tend to the psychosocial issues that impact terminally ill patients, including anxiety and depression. This health care trend include changes in the clinic setting such as the patient centered home medical model of care, but also extends in the hospital setting with the development of integrated palliative care programs that utilize social workers with specialized training as well.

One implication of this research is aimed at social work educators to continue to address the training and skill sets that are needed for social workers who care for patients with advanced disease. These social workers are in need for specialized education in assessments; developing treatment plans; and various appropriate therapeutic interventions that address the emotional and psychosocial issues of patients with advanced disease. Furthermore, due to the challenges of

working with the palliative care population, education and training on grief issues is imperative. Having high caliber social work staff interested in this area of social work is critical.

Another implication of this research may possibly impact the organization that the participants and researcher are employed with in order to develop new service lines, such as expansion of the current palliative care program and development of palliative care services within the patient centered home medical model that is currently being piloted at one of the local clinics. The findings of this research support the need to implement social work services in the clinic setting to assist the primary care providers with many psychosocial issues including the emotional needs of patients who have advanced disease. The majority of participants in this study appear to recognize the many benefits of having social work staff available to assist their patients with a variety of needs including: providing ongoing assessments of patients' anxiety and depression in between clinic appointments; offering counseling; arranging community services; and coordinating family meetings to establish treatment plans and clarify goals of care.

Furthermore, implications of this research impact physician education. This education should be multidimensional. First, efforts should be made to provide continuing education for primary care providers on the training and skill set of social workers. As reported in this study, the success of collaborative medical models depends on the level of physician support. If the primary care physicians have good relationships with social workers and have adequate information on their training and skill set, they will be more inclined to support the development of integrated and collaborative programs and will be more likely to advocate for the addition of social work staff on the medical health care teams.

Secondly, primary care provider education should focus on the complexities of addressing anxiety and depression in patients who have advanced diseases. The education

should focus on the impact of physician bias, transference, and nihilism and how these issues may impact the assessment of anxiety and depression, as well as providing patients with the appropriate pharmacological and psychological interventions as soon as possible. Furthermore, the education needs to address the challenges of identifying psychological distress in this patient population because of the impact of the medical disease and associated treatment side effects. Moreover, primary care providers should have the most up-to-date information on treatment options for palliative care patients, especially in light of their short life expectancy.

In addition to primary care provider education, another implication for social work is the role of patient and family education. Patients often do not recognize themselves as having anxiety or depression (McQuaid, et al., 1999). Some patients believe that any anxiety and depression that they may be experiencing is a normal and expected part of the dying process (Lyness, 2007) so may under-report their level of distress or may not disclose any information about their psychological distress as they may attribute these symptoms as related to the medical disease or treatment side effects (Hotopf, et al., 2002). Providing education on anxiety and depression for patients who have advanced disease may help to identify psychological distress earlier and get the patient the appropriate treatment and therapeutic intervention which may improve their overall quality of life, enhance their ability to cope with the medical disease and prepare for end of life.

There are several findings from this research that may need to be investigated further such as exploration of therapeutic nihilism (the belief that psychological distress is to be expected and a normal experience for a person who is dying) (Block, 2000) and its effect on the identification and treatment of anxiety and depression in patients who have advanced disease. Furthermore, it may be important to consider the aspect of culture, whether ethnicity or the



culture of the community, in this case, a rural area, and the meaning of “therapy” for the population in order to better “meet them where they’re at.” Another finding that may need to be explored further is the likelihood that various primary care providers have different definitions of “palliative care” and different perspectives of what types of patients should be considered to be “palliative”. Furthermore, additional research may need to be done to explore the role of family and their feelings of anxiety and depression and their impact on the outcome of office visits with the physician.

This study looked at how primary care providers identify and treat anxiety and depression in patients who have advanced disease. Primary care providers were interviewed and asked to provide their perspectives, however, a more thorough examination of this process may have been obtained had the researcher also interviewed patients of these providers to examine whether the patients feel their psychological and emotional needs were being met by their provider.

### **Study Strengths and Limitations**

The strength of using a qualitative approach in this research allowed for further exploration, analysis and interpretation of the processes that primary care physicians use to diagnose and treat anxiety and depression that cannot be explained by quantitative or numerical means (Anderson, 2010). The qualitative research method allowed the researcher to look at the processes in depth which provides rich information that cannot be adequately accessed through a written survey. This approach helped provide a better understanding of the physicians’ and other primary care providers’ experiences through the analysis of the words the respondents choose and the themes that they identify through the interview process (“Strengths and Weaknesses of Qualitative Research”, n.d.; Berg, 2009). Furthermore, while not the sole purpose of this

research, the data collected will provide information for the clinic to determine potential service line changes.

There were several limitations of this study. The nature of a qualitative approach limits the number of participating respondents and creates a homogeneous sample; therefore the resulting data cannot be generalized to the larger population of all clinics. This research collected data from targeted primary care providers in two small rural clinic settings and is most likely not representative of primary care practice in other areas of the country or larger medical practices. Furthermore, while there were two primary care clinics that were invited to participate in this study, there were no participants from the clinic that is currently piloting the patient centered home model of care. The lack of participants from this clinic does not allow for any type of comparison between the traditional model and the patient centered model of medical care. Also, the providers that did participate in this study were seasoned medical providers and their perspective may be quite different than a provider who is new to their practice, thus limiting any comparison in this regard as well. Moreover, these interviews were quite brief. The limited interview may not have allowed the provider time to feel comfortable sharing feelings about the role of transference, compassion fatigue or other personal feelings about these issues. Another limitation of this study included the possible influence of the researcher's personal biases in relation to the utilization of social work and mental health services and professional work with patients who have advanced disease. Also, due to the close working relationship between the researcher and the respondents, there is a possibility that this relationship influenced responses and reactions of both the respondents and the interviewer. This study was from the primary care providers' perspectives and does not include their patients' perspectives about the identification of their anxiety and depression or outcomes of interventions prescribed.

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## APPENDIX A. Consent Form

Institutional Review Board



### CONSENT FORM

Please read this form and ask any questions you may have before agreeing to participate in the study.  
Please keep a copy of this form for your records.

<b>Project Name</b>	Physician Identification and Treatment Methods of Anxiety and Depression in Patients with Advanced Disease: Utilization of Social Work Services	<b>IRB Tracking Number</b>	284744-1
<b>General Information Statement about the study:</b>			
This study is to examine the process that primary care providers use to identify anxiety and depression in patients with advanced diseases and to further understand their methods of treating these mental health issues including their utilization of social work and mental health services to treat these patients.			
You are invited to participate in this research. You were selected as a possible participant for this study because: You are a primary care provider in a medical clinic setting.			
<b>Study is being conducted by:</b>		Colette Zunk	
<b>Research Advisor (if applicable):</b>		Professor Jessica Toft	
<b>Department Affiliation:</b>		School of Social Work	
<b>Background Information</b>			
The purpose of the study is:			
The purpose of this study is to look at several areas in the primary care setting regarding anxiety and depression in patients who have advanced disease. Areas that will be considered include how primary care providers assess and identify anxiety and depression in patients with advanced disease. This study will also examine what treatment methods primary care providers use in treating anxiety and depression in this patient population, including their usage of social work or mental health services.			
<b>Procedures</b>			
If you agree to be in the study, you will be asked to do the following: <i>State specifically what the subjects will be doing, including if they will be performing any tasks. Include any information about assignment to study groups, length of time for participation, frequency of procedures, audio taping, etc.</i>			
Participate in an interview of approximately 45 minutes which will be audiotaped to ensure an accurate recording of the interview.			
<b>Risks and Benefits of being in the study</b>			
The risks involved for participating in the study are:			

None	
The direct benefits you will receive from participating in the study are:	
None	
<b>Compensation</b>	
Details of compensation (if and when disbursement will occur and conditions of compensation) include: <i>Note:</i> In the event that this research activity results in an injury, treatment will be available, including first aid, emergency treatment and follow-up care as needed. Payment for any such treatment must be provided by you or your third party payer if any (such as health insurance, Medicare, etc.).	
None	
<b>Confidentiality</b>	
The records of this study will be kept confidential. In any sort of report published, information will not be provided that will make it possible to identify you in any way. The types of records, who will have access to records and when they will be destroyed as a result of this study include:	
The interviews will be audiotaped and transcribed verbatim for data analysis. Audiotapes will be destroyed no later than June 1, 2012. Transcripts will be kept indefinitely in a locked file. To ensure confidentiality, the audiotapes, transcripts, research records and data will be kept in a locked file and password protected computer system in the researcher's home. Only the data will be shared in the research presentation, all names and other identifying information will be de-identified in order to ensure confidentiality.	
<b>Voluntary Nature of the Study</b>	
Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with any cooperating agencies or institutions or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until the date\time specified in the study. You are also free to skip any questions that may be asked unless there is an exception(s) to this rule listed below with its rationale for the exception(s).	
If you decide to participate and later decide to withdraw from the study, you will need to notify the researcher within one week after the interview to have your data withdrawn. Your participation in this study is strictly voluntary and there is no obligation to participate. Your participation in this study will not be shared with any other staff members of the clinic or institution.	
Should you decide to withdraw, data collected about you	will be used in the study
<b>Contacts and Questions</b>	
You may contact any of the resources listed below with questions or concerns about the study.	
Researcher name	
Researcher email	
Researcher phone	
Research Advisor name	Professor Jessica Toft
Research Advisor email	jetoft@stthomas.edu
Research Advisor phone	651-962-5803
UST IRB Office	651.962.5341

Institutional Review Board



Statement of Consent			
I have read the above information. My questions have been answered to my satisfaction and I am at least 18 years old. I consent to participate in the study. By checking the electronic signature box, I am stating that I understand what is being asked of me and I give my full consent to participate in the study.			
Signature of Study Participant <input type="checkbox"/> <i>Electronic signature</i>		Date	
Print Name of Study Participant			
Signature of Parent or Guardian (if applicable) <input type="checkbox"/> <i>Electronic Signature</i>		Date	
Print Name of Parent or Guardian (if applicable)			
Signature of Researcher <input type="checkbox"/> <i>Electronic signature*</i>		Date	
Print Name of Researcher		Colette Zunk	

\*Electronic signatures certify that:

The signatory agrees that he or she is aware of the policies on research involving participants of the University of St. Thomas and will safeguard the rights, dignity and privacy of all participants.

- The information provided in this form is true and accurate.
- The principal investigator will seek and obtain prior approval from the UST IRB office for any substantive modification in the proposal, including but not limited to changes in cooperating investigators/agencies as well as changes in procedures.
- Unexpected or otherwise significant adverse events in the course of this study which may affect the risks and benefits to participation will be reported in writing to the UST IRB office and to the subjects.
- The research will not be initiated and subjects cannot be recruited until final approval is granted.



## **APPENDIX B. Study Participation Recruitment Invitation Script**

I plan to present information about my study at a primary care provider department meeting and then will follow up on an individual basis in recruitment efforts. The following is the script that I will use at the department meeting as well as the follow up contact.

### **Thank you for allowing me to attend your Friday morning meeting.**

My name is Colette Zunk and I am in my final year of the Masters of Social Work program at the University of St. Thomas/College of St. Catherine in St. Paul. My research chair is Professor Jessica Toft. The final year involves a research project. I am conducting a study to examine how primary care providers assess and identify anxiety and depression in patients with advanced disease. This study will also examine what methods primary care providers' use in treating anxiety and depression in this patient population, including their usage of social work or mental health services. I would like to invite you to participate in this research. You were selected as possible participants because you are a primary care provider and have knowledge and/or experience in working with patients who have advanced diseases and your location is convenient for me to do my research and data collection.

There are no known risks or benefits to participate in this research. There is no obligation to participate in the study. To ensure confidentiality, your participation in this study will not be shared to any clinic or hospital administrative or staff member. The interview can take place in the setting of your choice, again to protect your confidentiality.

If you agree to be in this study, I will ask you to participate in an interview that will take approximately 45 minutes to an hour. The interview will be audiotaped to ensure an accurate recording of the interview. The audiotapes will be transcribed verbatim by me and analysed.



Only the data findings will be included in the final research paper. Your name or any other identifying information will be de-identified. The clinical findings will be presented at the MSW Clinical Presentation Day in May, 2012.

All audiotapes, transcripts and other research data will be stored in a locked file and password protected computer at my home. You have the right and opportunity to stop the interview at any time and should you decide to no longer be involved in the project after the interview has been conducted, you will have one week after the interview to notify me that you wish your data to be withdrawn from the study.

I wanted to opportunity to present information about this research project to you as a group but I am not asking anything of you today. I want to stress the fact that participation in this study is strictly voluntary and I do not want you to feel obligated to participate because of any working relationship that we have. To make the study viable, per the School of Social Work at UST, the goal is to have about 10 study participants. I understand that it is not easy to decline when asked to participate in person, therefore, I will be sending an email invitation to each of you (and to the providers at the Tomahawk Clinic/Rhineland Clinic) to ask for your participation. Although your contributions to the study would be greatly appreciated, participation is strictly voluntary and no offense will be taken if you decline. Thank you for the opportunity to discuss this research project at this meeting. If you have any questions, feel free to contact me at any time.

**Email Invitation**

I wish to invite you to participate in my research project. I am conducting a study to examine how primary care providers assess and identify anxiety and depression in patients with advanced disease. This study will also examine what methods primary care providers' use in treating anxiety and depression in this patient population, including their usage of social work or mental health services. I would like to invite you to participate in this research. You were selected as possible participants because you are a primary care provider and have knowledge and/or experience in working with patients who have advanced diseases and your location is convenient for me to do my research and data collection.

There are no known risks or benefits to participate in this research. There is no obligation to participate in the study. To ensure confidentiality, your participation in this study will not be shared to any clinic or hospital administrative or staff member. The interview can take place in the setting of your choice, again to protect your confidentiality.

If you agree to be in this study, I will ask you to participate in an interview that will take approximately 45 minutes to an hour. The interview will be audiotaped to ensure an accurate recording of the interview. The audiotapes will be transcribed verbatim by me and analysed. Only the data findings will be included in the final research paper. Your name or any other identifying information will be de-identified. The clinical findings will be presented at the MSW Clinical Presentation Day in May, 2012.

All audiotapes, transcripts and other research data will be stored in a locked file and password protected computer at my home. You have the right and opportunity to stop the interview at any time and should you decide to no longer be involved in the project after the

interview has been conducted, you will have one week after the interview to notify me that you wish your data to be withdrawn from the study.

If you are willing to participate in this research study please contact me either through email or in person. My direct extension is 62657.

Thank you for considering contributing to this research project.

Colette Zunk, CSW  
Palliative Care Specialist

**For providers who agree to participate:**

For those who agree to participate in the study and the interview has been scheduled. I will ask each participant to read the consent form and inform them to feel free to ask questions prior to participation in the study. I will review the purpose of the study once again. They will be reminded that they can opt out at any point of the interview and up to one week after the interview.

## APPENDIX C. Ministry Health Care IRB Approval Form

### EXPEDITED REVIEW APPROVAL FORM FOR IRB REVIEWERS

Study PRO #: St. Thomas 284744-1

Principal Investigator: Colette Zunk

Principal Investigator's Department: Palliative Care

**Documentation: Mark every criterion that is satisfied**

**Submission Type:**

New Protocol     Amendment AME#              Continuing Progress Report CPR#         

**Review criteria:**     FDA regulated? (use FDA)     All others: use HHS

**New Protocols:**

All 8 criteria for IRB approval of research are satisfied: HHS 45 CFR 46.111(a) or FDA 21 CFR 56.111(a)

Vulnerable populations?  No     Yes If Yes, define:         

Prisoners are subjects and study may not be expedited.

45 CFR 46 Subpart B (pregnant women, fetuses, neonates) applies and the specific regulatory requirements have been met.

45 CFR 46 Subpart D (children) applies; note the approval category and state why it applies:

404    405    406    407         

Study involves other vulnerable subjects and adequate extra protections are provided (45 CFR 46.111(b) or 21 CFR 56.111(b)) as described in the study.

The proposed management and possible reporting of information relevant to the protection of human subjects is adequate.

The project is receiving funding. Please indicate funding source:

<input type="checkbox"/> Department Funds	<input type="checkbox"/> For Profit	<input type="checkbox"/> Federal • <input type="checkbox"/> NIH • <input type="checkbox"/> DoD • <input type="checkbox"/> EPA • <input type="checkbox"/> DoEd • <input type="checkbox"/> DoJ • <input type="checkbox"/> BoP • <input type="checkbox"/> DoE	<input type="checkbox"/> Federal Pass-through • <input type="checkbox"/> NIH • <input type="checkbox"/> DoD • <input type="checkbox"/> EPA • <input type="checkbox"/> DoEd • <input type="checkbox"/> DoJ • <input type="checkbox"/> BoP • <input type="checkbox"/> DoE	<input type="checkbox"/> Internal	<input type="checkbox"/> Local	<input type="checkbox"/> Non- Profit	<input type="checkbox"/> State
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a. Is the new funding coming from a Clinical Trials Contract (funding type: For Profit)? Yes  No

• If Yes, has the HRPP office has reviewed the contract and compare with Informed Consent Form to ensure consistency. Yes  No

o *If no, or If the contract is still a draft, the project can not be approved until the final contract is executed.*

Approval is granted for **1 year** (not to exceed 365 days)

The relevant category(ies) is: (see *Expedited Applicability and Research Regulations – next page*):

1(a)  1(b)  2(a)  2(b)  3  4  5  6  7

**Additional Considerations for new protocols:**

All criteria for Informed Consent document are satisfied: 45 CFR 46.116(a,b) or 21 CFR 50.25

Waiver of Informed Consent granted for recruitment only

Waiver of HIPAA Authorization granted for recruitment only

Waiver of Informed Consent procedure granted: HHS 45 CFR 46.116(c, d)

Waiver of Informed Consent Documentation granted (e.g., verbal consent, unsigned consent letter):

**EITHER** (45 CFR 46.117(c))

The only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether they want documentation linking them with the research, and the subject's wishes will govern.

**OR** (45 CFR 46.117(c) or 21 CFR 56.109(c)(1))

The research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside the research context.

Waiver of HIPAA Authorization granted (for accessing or creating PHI) 45 CFR 164.512(i)(2)(ii).

Other HIPAA pathway (Limited Data Set, deceased subjects, no PHI accessed or created) 45 CFR 164.514(e), 45 CFR 164.512(i)(2)(iii)

**Amendment:**

The protocol remains a) no greater than minimal risk AND b) qualified for expedited review.

Consent form(s) were revised.

**Continuing Progress Reports:**

Cumulative enrollment, withdrawals, Unanticipated Problems, Reportable Events, Amendments, have been reviewed.

All 8 criteria for IRB approval of research remain satisfied. HHS 45 CFR 46.111(a) or FDA 21 CFR 56.111(a)

Protocol remains no greater than minimal risk, and benefits outweigh risks.

This study involves  Consent form(s)  Waiver of consent/HIPAA

Final Report

Approval is granted for **\_\_\_\_\_** (not to exceed 365 days).

The relevant category(ies) are: (see *Expedited Applicability and Research Regulations – below*):

1(a)  1(b)  2(a)  2(b)  3  4  5  6  7  8(a)  8(b)  8(c)  9

**Expedited Review Procedure - Applicability:** Source: 63 FR 60364-60367, November 9, 1998.

A(1)	Research activities that present no more than minimal risk to human subjects.
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A(2)	Research activities that involve only procedures listed in one or more of the following categories may be reviewed by the IRB through the expedited review procedure. The activities listed should not be deemed to be of minimal risk simply because they are included on this list. Inclusion on this list merely means that the activity is eligible for review through the expedited review procedure when the specific circumstances of the proposed research involve no more than minimal risk to human subjects.
B	The categories in this list apply regardless of the age of subjects, except as noted.
C	The expedited review procedure may not be used where identification of the subjects and/or their responses would reasonably place them at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, insurability, reputation, or be stigmatizing, unless reasonable and appropriate protections will be implemented so that risks related to invasion of privacy and breach of confidentiality are no greater than minimal.
D	The expedited review procedure may not be used for classified research involving human subjects.
E	IRBs are reminded that the standard requirements for informed consent (or its waiver, alteration, or exception) apply regardless of the type of review – expedited or convened – utilized by the IRB.
F	Categories one (1) through seven (7) pertain to both initial and continuing IRB review.

#### Expedited Review Procedure - Research Categories:

1(a)	Clinical studies of drugs and medical devices when research on drugs for which an investigational new drug application (21 CFR Part 312) is not required. Note: Research on marketed drugs that significantly increases the risks or decreases the acceptability of the risks associated with the use of the product is not eligible for expedited review.
1(b)	Clinical studies of drugs and medical devices when research on medical devices for which (i) an investigational device exemption application (21 CFR Part 812) is not required; or (ii) the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.
2(a)	<b>Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture</b> from healthy, nonpregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week.
2(b)	<b>Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture</b> from other adults and children considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.
3	<b>Prospective collection of biological specimens for research purposes by noninvasive means.</b> Examples: (a) hair and nail clippings in a nondisfiguring manner; (b) deciduous teeth at time of exfoliation or if routine patient care indicates a need for extraction; (c) permanent teeth if routine patient care indicates a need for extraction; (d) excreta and external secretions (including sweat); (e) uncannulated saliva collected either in an unstimulated fashion or stimulated by chewing gumbase or wax or by applying a dilute citric solution to the tongue; (f) placenta removed at delivery; (g) amniotic fluid obtained at the time of rupture of the membrane prior to or during labor; (h) supra- and subgingival dental plaque and calculus, provided the collection procedure is not more invasive than routine prophylactic scaling of the teeth and the process is accomplished in accordance with accepted prophylactic techniques; (i) mucosal and skin cells collected by buccal scraping or swab, skin swab, or mouth washings; (j) sputum collected after saline mist nebulization.
4	<b>Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing.</b> (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications.) Examples: (a) physical sensors that are applied either to the surface of the body or at a distance and do not involve input of significant amounts of energy into the subject or an invasion of the subject's privacy; (b) weighing or testing sensory acuity; (c) magnetic resonance imaging (d) electrocardiography, electroencephalography, thermography, detection of naturally occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography; (e) moderate exercise, muscular strength testing, body composition assessment, and flexibility testing where appropriate given the age, weight, and health of the individual.

5	<b>Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes</b> (such as medical treatment or diagnosis).
6	<b>Collection of data from voice, video, digital, or image recordings made for research purposes.</b>
7	<b>Research on individual or group characteristics or behavior</b> (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) <b>or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.</b> (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. This listing refers only to research that is not exempt.)
8(a)	<b>Continuing review of research previously approved by the convened IRB</b> where (i) the research is permanently closed to the enrollment of new subjects; (ii) all subjects have completed all research-related interventions; and (iii) the research remains active only for long-term follow-up of subjects.
8(b)	<b>Continuing review of research previously approved by the convened IRB</b> where no subjects have been enrolled and no additional risks have been identified.
8(c)	<b>Continuing review of research previously approved by the convened IRB</b> where the remaining research activities are limited to data analysis.
9	<b>Continuing review of research</b> , not conducted under an investigational new drug application or investigational device exemption where categories two (2) through eight (8) do not apply <b>but the IRB has determined and documented at a convened meeting that the research involves no greater than minimal risk and no additional risks have been identified.</b>

<b>Reviewer comments</b>

Name of reviewer: Susan McCarthy, CITI CertifiedDate: 11/29/11

## APPENDIX D. Agency Consent Form

Institutional Review Board



### Agency CONSENT FORM

**Researcher:** Please provide your agency with the information about your project and have your agency contact complete this form.

**Agency:** Please read this form and ask any questions you may have before agreeing to allow this study to take place at your agency. Please keep a copy of this form for your records.

<b>Project Name</b>	Physician Identification and Treatment Methods of Anxiety and Depression in Patients with Advanced Disease: Utilization of Social Work Services	<b>IRB Tracking Number</b>	284744-1
<b>General Information Statement about the study:</b>			
Identifying and treating anxiety and depression is a very important issue for patients who have advanced diseases, yet these issues are often unrecognized due to a variety of factors. The issue of recognizing and treating anxiety and depression in patients with advanced disease has particular relevance to social work in various capacities including medical social work, such as hospice and palliative care services; outpatient behavioral health programs; oncology centers; dialysis clinics; etc. Further research is necessary to explore the relationship between the primary care provider's training in identifying anxiety and depression in patients with end stage diseases and their usage of mental health and social work services. Primary care providers in this study will refer to Internal Medicine Physicians, Family Practice Physicians, Nurse Practitioners and Physician Assistants in the primary care setting.			
Your agency is invited to participate in this research. The agency was selected as a host for this study because:			
Ministry Medical Group in Rhinelander and Tomahawk was selected as a host for this study because of the close proximity to the researcher as well as the researcher's familiarity with these clinics. Moreover, how primary care providers assess and treat anxiety and depression is the focus of this study, and this organization houses a number of primary care medical providers.			
Study is being conducted by:	Colette Zunk		
Research Advisor (if applicable):	Jessica Toft		
Department Affiliation:	Social Work		
<b>Background Information</b>			
The purpose of the study is:			
The purpose of this study is to look at several areas in the primary care setting regarding anxiety and depression in patients who have advanced disease. Areas that will be considered include how primary care providers assess and identify anxiety and depression in patients with advanced disease. This study will also examine what treatment methods primary care providers use in treating anxiety and depression in this patient population, including their usage of social work or mental health services.			



<b>Procedures</b>	
Study participants will be asked to do the following: <i>State specifically what the subjects will be doing, including if they will be performing any tasks. Include any information about assignment to study groups, length of time for participation, frequency of procedures, audio taping, etc.</i>	
Study participants will be asked to participate in a one-time interview that will last approximately 45 -60 minutes. The interview will be scheduled at a time and location that is most convenient for the provider and will be audiotaped to ensure an accurate recording of the interview.	
<b>Risks and Benefits of being in the study</b>	
The risks involved for subjects participating in the study are:	
None	
The direct benefits the agency will receive for allowing the study are:	
None	
<b>Compensation</b>	
Details of compensation (if and when disbursement will occur and conditions of compensation) include:	
None	
<b>Confidentiality</b>	
The records of this study will be kept confidential. The types of records, who will have access to records and when they will be destroyed as a result of this study include:	
The interviews will be audiotaped and transcribed verbatim for data analysis. Audiotapes will be destroyed no later than June 1, 2012. Transcripts will be kept indefinitely in a locked file at the researcher's home. To ensure confidentiality, the audiotapes, transcripts, research records and data will be kept in a locked file and password protected computer in the researcher's home. Only the data will be shared in the research presentation, all names and other identifying information will be de-identified in order to ensure confidentiality.	
<b>Voluntary Nature</b>	
Allowing the study to be conducted at your agency is entirely voluntary. By agreeing to allow the study, you confirm that you understand the nature of the study and who the participants will be and their roles. You understand the study methods and that the researcher will not proceed with the study until receiving approval from the UST Institutional Review Board. If this study is intended to be published, you agree to that. You understand the risks and benefits to your organization.	
Any providers who decide to participate and later decide to withdraw from the study, will need to notify the researcher within one week after the interview to have their data withdrawn. Provider participation in this study is strictly voluntary and there is no obligation to participate. Provider participation in this study will not be shared by the researcher with any administrative or other staff members of the clinic or hospital.	
Should you decide to withdraw, data collected about you	will be used in the study

<b>Contacts and Questions</b>			
You may contact any of the resources listed below with questions or concerns about the study.			
Researcher name			
Researcher email			
Researcher phone			
Research Advisor name	Jessica Toft		
Research Advisor email	jetoft@stthomas.edu		
Research Advisor phone	651-962-5803		
UST IRB Office	651.962.5341		
<b>Statement of Consent</b>			
I have read the above information. My questions have been answered to my satisfaction and I consent to allow the study to be conducted at the agency I represent. By checking the electronic signature box, I am stating that I understand what is being asked of me and I give my full consent.			
Signature of Agency Representative		Date	
<input checked="" type="checkbox"/> <i>Electronic signature</i>			
Print Name of Agency Representative	Robert Sookochoff MD, Regional VP-NR MMG 11/17/11		
Signature of Researcher		Date	
<input checked="" type="checkbox"/> <i>Electronic signature*</i>			
Print Name of Researcher			

\*Electronic signatures certify that:

The signatory agrees that he or she is aware of the policies on research involving participants of the University of St. Thomas and will safeguard the rights, dignity and privacy of all participants.

- The information provided in this form is true and accurate.
- The principal investigator will seek and obtain prior approval from the UST IRB office for any substantive modification in the proposal, including but not limited to changes in cooperating investigators/agencies as well as changes in procedures.
- Unexpected or otherwise significant adverse events in the course of this study which may affect the risks and benefits to participation will be reported in writing to the UST IRB office and to the subjects.
- The research will not be initiated and subjects cannot be recruited until final approval is granted.



## APPENDIX E. Qualitative Research 682 Interview Questions

- 1) What is your educational background?
- 2) How long have you been practicing medicine?
- 3) What types of communities have you practiced medicine in?
- 4) I'm interested in the type of formal and informal training you have received in identifying and treating anxiety and depression in patients with end stage diseases.

Have you ever received training to identify anxiety and depression among your patients with end-stage diseases? If 'yes': What kind of training have you received?

Outside of the training you just discussed, could you tell me about any other education you have received on the topic such as through conferences, workshops, and Continuing Medical Education sessions?

Have you read any articles on this topic in the last three to five years?

- 5) This study is looking at the issue of anxiety and depression in patients with advanced diseases. What percentage of your patients do you think experience anxiety and depression at the end of life? How much of an issue do you think it is? Explain.
- 6) In an office visit, do you spend time addressing anxiety and depression issues with palliative care patients? If no, move down to a later question. If yes: how much time do you spend discussing anxiety and depression issues? Explain how addressing these issues affect the overall outcome of the office visit?
- 7) I'm interested in what your process is to identify anxiety and depression in patients with end stage diseases.

What tools do you use to identify and diagnosis anxiety and depression?  
(HADS-Hospital Anxiety & Depression Scale; Beck Depression Scale; Other)

Do you use any of these screening or diagnostic tools with patients who have been diagnosed with end stage diseases? If so, which ones? If not, how do you identify these issues?

Describe for me your general level of comfort in identifying and treating anxiety and depression in your patients with advanced disease?

- 8) As a patient's disease progresses, does your approach in addressing these issues change? If no- proceed to the next question. If yes, please describe the differences in your approach. What signs or symptoms of anxiety and depression do you look for in advanced stages of illness?
- 9) Describe what is your preferred method for treating anxiety and depression in your patients with end stage diseases?
- 10) What do you look for to determine whether you are adequately addressing anxiety and depression in your patients who have advanced diseases?
- 11) Do you have a process for following up with these patients to see how they are managing with their anxiety and depression in between office visits? If no, proceed to next question. If yes: Please describe the type of follow up that is provided in between office visits?
- 12) I'm interested in your thoughts on recommending social work or mental health services for patients who have anxiety and depression at the end of life.

Do you feel social work or mental health services could be of benefit to these patients? If so, how?

Do you have a process for utilizing social work or mental health support services in addressing anxiety and depression with your patients? If so, what is it?

Are there any other issues that prevent you or get in the way of using social work or mental health services for your terminal patients with anxiety and depression?

- 13) The research states that there are multiple factors that affect providers' decisions related to emotional needs of patients at the end of life from productivity quotas to providers' own concern about emotional upset. In your practice, what are your personal incentives and disincentives regarding assessing patients for anxiety and depression during an office visit?
- 14) What do you feel would be helpful to your practice in assisting patients with anxiety and depression at end stage disease processes?
- 15) Do you have anything else that you would like to add regarding the issue of anxiety and depression in patients who have advanced disease?