THE PREVALANCE OF DEPRESSION AMONGST PEOPLE WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE ON LONG TERM OXYGEN THERAPY

by

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ABSTRACT

Aim

To determine the prevalence of depression amongst people with chronic obstructive pulmonary disease (COPD) on long term oxygen therapy (LTOT) and examine the differences and relationships between depressed and not depressed patients to inform clinical practice.

Methods

In September 2009 a cross-sectional point prevalence study of the total District Health Board (DHB) population of COPD patients on LTOT oxygen in a large urban area in New Zealand (NZ) was conducted. Depression was assessed using the self-completed Patient Health Questionnaire (PHQ-9). Additional clinical and demographic characteristics were obtained from hospital records and a self-completed questionnaire.

Results

Sixty three patients (36 females, mean age 72) from the total population of 73 with severe COPD (forced expiratory volume in one second [FEV1] 37% predicted) completed the survey. PHQ-9 results indicate the total prevalence of depression was 54%; 95% CI 41.71-65.87. Twenty five percent of patients had mild depression and 29% had moderate to severe depression. One in six patients of those who screened positively was being treated for depression. No significant correlations or differences were found between the depressions scores and the demographic (age, gender, lives alone) or clinical (portable oxygen, time on oxygen, hospital admissions, pulmonary rehabilitation and FEV1) characteristics.

Conclusion

This study provides new evidence regarding the prevalence of depression in NZ COPD LTOT populations. Depression symptoms and depression are highly prevalent in this patient population and there is evidence depression is undertreated. The PHQ-9 is a simple and effective tool community nurses can use for the initial screening of depression, which could improve the recognition and possible uptake of effective interventions to lessen the impact of depression in this population. The PHQ-9 is validated screening tool that should be used in further depression prevalence research with NZ COPD and other long-term condition populations to determine homogeneity across studies.

Key words: Chronic obstructive pulmonary disease, long term oxygen therapy, depression, prevalence, screening

ACKNOWLEDGEMENTS

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CHAPTER 1 – INTRODUCTION

Studies and clinical practice confirm chronic obstructive pulmonary disease (COPD) is a variable yet generally progressive condition with pulmonary (i.e. airflow limitation and impaired gas exchange) and extra pulmonary effects (i.e. osteoporosis and depression) that cause sufferers significant morbidity and mortality (National Institutes of Health [NIH], 2007). The cardinal symptom of the reduced lung function is breathlessness, which leads people with COPD to reduce their activities, thereby becoming deconditioned and socially isolated. Impaired gas exchange late in the disease can lead to chronic hypoxia. The hypoxia can be partially treated, bringing a person's blood oxygen level up (>60mmHg) with long term oxygen therapy (LTOT) thus preventing early organ damage and death and hopefully improving the person's quality of life. This treatment requires adherence to a prescription of low flow oxygen administration delivered continuously, usually via an electric oxygen concentrator with long plastic tubing and nasal prongs which a person is connected to for over 15 hours per day, for life. Living with the symptoms of COPD and the restrictions imposed by oxygen therapy potentially contributes to developing depression.

This thesis reports on a cross-sectional point prevalence study examining the prevalence of depression amongst people with COPD on LTOT, in a large urban region in New Zealand (NZ), Wellington. Ethics approval for this study was granted in July 2009 by the Central Regional Ethics Committee (Appendix 1). This study's primary aim was to determine the prevalence of depression amongst people with COPD on LTOT in a large urban area in NZ. The objectives were:

- to describe the characteristics of depressed and non-depressed people (i.e. ethnicity, age gender, disease severity), thereby improving understanding about the occurrence and variation of depression prevalence for NZ people with COPD on long term oxygen therapy;
- to inform the introduction of validated depression screening tool as standard in practice;
- to inform future service provision for COPD LTOT patients in the community; and
- to provide new knowledge of the prevalence of depression in the NZ COPD LTOT population and add to the total body of knowledge on the prevalence of depression in chronic obstructive pulmonary disease.

Depression is a common and treatable mental disorder (American Psychiatric Association [APA], 2000). There is considerable variability with regard to the reported prevalence, clinical recognition and access to treatment of depression for people with chronic obstructive pulmonary disease. Depression is characterised by changes in mood, thinking and activity, significant enough to impact on a person's ability to take care of his or her everyday needs and responsibilities. Provision of timely diagnosis and treatment maybe assisted with the use of validated depression assessment tools for people with COPD in practice.

Background and significance of this research

The study was undertaken primarily to better understand the extent of depression in the COPD LTOT patient population. A critical examination of the published research about depression in COPD, identified gaps relating to the overall knowledge of the prevalence of depression for people with COPD on long term oxygen therapy. Specifically, no published studies conducted in NZ were found. This study's findings will inform potential service improvements including: 1) increased accessibility to the types of services (i.e. pulmonary rehabilitation) offered for people with COPD on LTOT which are known to improve clinical outcomes, and 2) the decision to introduce the use of a validated depression screening tool as standard in practice with the aim of improving the identification, referral and uptake of treatments for depression in this population.

The burden and classification of COPD

The World Health Organisation estimates that COPD will be the fifth worldwide cause of disability adjusted life years lost and the third worldwide cause of mortality by 2020 (Murray & Lopez, 1997). Currently COPD is the fourth leading cause of death in the world (NIH, 2007). In NZ COPD affects at least 200,000 people over the age of 45 years. Based on NZ hospital admission data the prevalence of COPD for Māori is twice the rate for non-Māori; hospitalisation for Māori occurs at younger ages and the rate of admission increases more steeply with age than for non-Māori (Town, Taylor, Garrett, & Patterson, 2003).

The diagnosis of COPD is based on a person's history, symptoms and the documentation of a post bronchodilator spirometry forced expiratory volume in one second / forced vital capacity (FEV1/FVC) <70% and severity is staged as FEV1% of the predicted normal as shown in Figure 1.1.

Spirometry reference values are determined from the patient's age, sex and height:
1. Mild COPD FEV1/FVC < 0.70
   FEV1 ≥ 80% predicted at this stage, the patient may not be aware that their lung function is abnormal.

2. Moderate COPD FEV1/FVC < 0.70
   50% ≤ FEV1 < 80% predicted symptoms usually progress at this stage, with shortness of breath usually developing on exertion.

3. Severe COPD FEV1/FVC < 0.70
   30% ≤ FEV1 < 50% predicted shortness of breath classically worsens at this stage and often limits patients' every day activities. Exacerbations are especially seen beginning at this stage.

4. Very Severe COPD FEV1/FVC < 0.70
   FEV1 < 30% predicted *or* FEV1 < 50% predicted plus chronic respiratory failure (need to consider assessment for oxygen therapy). At this stage, quality of life is very noticeably impaired and exacerbations may be life-threatening.

Figure 1.1: Diagnosis and staging of COPD
Adapted from: The Global Obstructive Lung Disease (GOLD) Spirometric Criteria for COPD Severity (National Institutes of Health, 2007). www.goldcopd.com/download.asp?intId=445

Care context for people with COPD on long term oxygen therapy

In the Wellington region Capital & Coast District Health Board (C & C DHB) Community Health Service (CHS) provide long term oxygen therapy. The CHS is joined to the local hospital and delivers 'home care' services to people with COPD on LTOT who meet the clinical criteria for LTOT; these will be described in Chapter 2. Home care covers people living in their own homes and rest homes and generally excludes those living in residential hospital level care facilities that are contracted by the DHB to provide 24/7 nursing cover. The services provided by CHS are covered under the publically funded NZ health system and so people are not selected under any financial or social basis. The DHB serves a regional population of about 250,000 (http://www.ccdhb.org.nz/aboutus/Who.htm).

The community health nursing service employs 53.8 full time equivalent nurses who see over 6000 people per annum with acute, chronic and palliative care needs (Mold & Boland, 2009). The average annual visits per person seen by this service are 14; totalling over 80,000 community nursing visits per year. At any given time there are up to 140 people on LTOT under the care of the community health nursing service and approximately 60% of these will have chronic obstructive pulmonary disease.

I (the researcher) am the Respiratory Clinical Nurse Specialist for the Community Health Services. This role involves strategic and service planning, teaching, quality

components and the assessment and care of patients with respiratory conditions (in the main COPD) requiring specialist community nursing follow-up across the region. The service receive referrals from both primary and hospital settings. Within the CHS team I oversee the provision of oxygen and provide clinical expertise to the district nursing team regarding assessment, management and support of people receiving long term oxygen therapy. The set-up, routine assessments and afterhours support for people on LTOT is provided by the district nurses. The district nurses assisted with the data gathering of the research.

Overview of thesis

This introductory chapter has provided an overview of the context and background to this point prevalence study.

Chapter 2 presents an in-depth explanation of interrelated pathophysiology, symptoms and current best practice considerations in the clinical management of people with chronic obstructive pulmonary disease and depression.

Chapter 3 details and critiques the literature reviewed related to the overall current knowledge about the prevalence of depression for people with COPD on long term oxygen therapy. Specifically two similar studies are discussed in depth, guiding the rationale for the design of this study.

Chapter 4 details this study's observational research methodology, the sample, data collection method, data analysis and the steps taken to ensure the study's reliability and validity.

In Chapter 5 the results are presented. In addition to the depression score results, the chapter presents the findings concerning representativeness of the responders.

Chapter 6 discusses the findings in relation to the literature and clinical practice. Explanations are given for expected and unexpected results. The research design, processes and limitations are also discussed. Recommendations are provided for practice and future research.

CHAPTER 2 – CLINICAL MANAGEMENT OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

This thesis reports on a study designed to examine the prevalence of depression in chronic obstructive pulmonary disease (COPD) patients on long term oxygen therapy (LTOT) in a large urban area in New Zealand. This chapter provides a contextual in-depth explanation of the interrelated pathophysiology, symptoms and the current best practice considerations in the holistic clinical management of people with chronic obstructive pulmonary disease.

Definition and Pathophysiology of COPD

A frequently occurring and mainly non-reversible chronic lung disease; COPD is a complex of different pathophysiologies and clinical presentations, typically emphysema and chronic bronchitis. COPD is characterised by obstruction of lung airflow which interferes with normal breathing. The generally progressive history of COPD results in the widely recognised distressing symptoms of dyspnoea, chronic cough and sputum production. Figure 2.1 shows a simplified cycle of the individual effects often seen in this progressive condition. The most disabling symptom dyspnoea is experienced first with exercise (leading to reducing activities) and in severe disease with rest. In severe COPD, multi-system effects are evident and include malnutrition and muscle wasting which result in further dyspnoea and fatigue leading to significant deconditioning, increased exacerbations, anxiety and depression. Pulmonary hypertension and cor-pulmonale may also develop in advanced disease (NIH, 2007; O'Donnell, Revill, & Webb, 2001).

COPD symptoms typically arise from cigarette smoking which causes abnormal lung inflammation in susceptible people. This abnormal inflammatory response produces the physiological changes characteristic of COPD. These include mucus hypersecretion, ciliary dysfunction, airflow limitation, hyperinflation and impaired gas exchange. It is thought hyperinflation develops early in the disease and is the key mechanism behind exertional dyspnoea (NIH, 2007). In general, gas exchange worsens as the disease progresses and can result in hypoxemia and hypercapnia (respiratory failure). The development of respiratory failure is indicated by oxygen tensions (Pa02) <60mmHg with or without carbon dioxide tensions (PaC02) > 45mmHg taken as an arterial blood gas (ABG) while breathing air. Clinical signs of

respiratory failure or right sided heart failure include ankle swelling, increased jugular venous pressure (JVP) and central cyanosis (Brashers, 2002; NIH).

COPD

Dyspnoea

Reduced fitness

Reduced mobility
(*Deconditioned)*

Social isolation

Depression
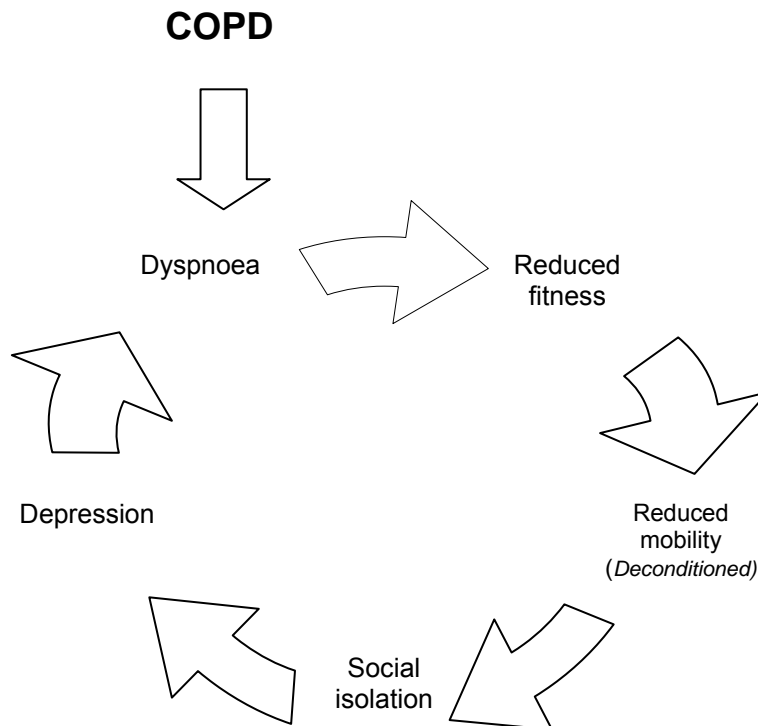
Figure 2.1: The cycle of physical, social and psychological costs of COPD
Adapted from: Global Initiative for Chronic Obstructive Lung Disease (National Health Institutes, 2007). www.goldcopd.com/download.asp?intId=442

Chronic hypoxemia causes pulmonary vasoconstriction and subsequently pulmonary hypertension with increasing strain and finally failure of the right ventricle (cor-pulmonale). Secondary polycythemia may develop and cause increased viscosity. Other organ systems are also affected in particular those with high metabolic demands such as brain, skeletal muscle and kidney (McKenzie et al., 2008).

Overview of management goals in stable COPD

COPD is a heterogeneous disease influenced by continued exposure to risk factors (i.e. occupational or smoking), the rate of exacerbations and co-morbid illness which affect individual patients in different ways. Management includes pharmacological and non pharmacological interventions which need to be individually guided to cover the impairments, disability and handicap of the primary disease and co-existing conditions (National Institute for Clinical Excellence [NICE], 2004). The outcomes aimed for in the management of COPD are symptom relief, improved quality of life, through improved functioning, prevention and treatment of exacerbations and

complications, and reduced mortality (Celli et al., 2004; McKenzie et al., 2008; NIH, 2007).

To date smoking cessation and LTOT for patients with chronic hypoxia are the only two factors shown to reduce mortality (NIH, 2007). The other interventions central to the day-to-day clinical management of COPD involve; addressing the underlying lung hyperinflation with bronchodilators and preventing exacerbations with other pharmacological (e.g. inhaled glucocorticosteriods) and non-pharmacological care (e.g. pulmonary rehabilitation), these interventions significantly influence the overall morbidity of the disease (Cooper & Dransfield, 2008).

Oxygen therapy in COPD

LTOT is prescribed for arterial hypoxemia in an attempt to prevent or postpone the derangements of chronic arterial hypoxemia with regard to end stage organ damage (Young, Crockett, & McDonald, 2005). The Ministry of Health (MOH) (2001a) criteria for the prescription of LTOT in COPD is an arterial blood gas result taken on room air showing a Pa02 of <55mmHg or 60mmHg with evidence of either right heart failure, pulmonary hypertension, or polycythemia. This criterion is based on two landmark trials; the American Nocturnal Oxygen Therapy Trial (NOTT, 1980) and the British Medical Research Council (MRC, 1981) trial. These trials demonstrated that domiciliary oxygen for at least 15 hours per day, improved survival of COPD patients with chronic hypoxia. LTOT in hypoxemic COPD patients has physiological benefits including, reduced pulmonary hypertension, reversal of polycythemia, improved exercise performance, increased body weight and improved neuropsychiatric functioning (Balter, Danidk, Chapman, Sorba & Rebuck, 1992; MRC, 1981; NOTT, 1980; Weidzeicha, 2000; Weitzenblum, Oswald, Apprill, Ratomaharo, & Kessler, 1991).

Over the past 20 years home LTOT has become the major treatment for COPD patients with hypoxemia. This in general confers being on oxygen for at least 15 hours a day for potentially many years. Current oxygen prescriptions within the Community Health Service (CHS) where this research was conducted date back as far as 1991. The May 2009 CHS oxygen database showed 42% of the LTOT patients have been on their treatment for over 5 years. Home LTOT presents both direct and indirect impacts on patient and carers; the impacts are both positive and negative. Along with cost, quality and equity issues for service providers; it remains for the health professionals who prescribe and initiate oxygen therapy to explore the details

of the real world of COPD patients on LTOT, so appropriate support and resources are targeted and co-ordinated correctly to result in positive outcomes for individuals receiving this treatment.

Adherence to recommended management in COPD

Oxygen prescription adherence can be variable, older studies have reported that the hours those on LTOT use it for are generally fewer than what is prescribed by study investigators or physicians (Gorecka, Gorselak, Sliwinski, Tobiasz, & Zielinski, 1997; NOTT, 1980). Restrick et al. (1993) interviewed 176 oxygen dependant patients who mostly had severe COPD and found that 45% were housebound and many had issues with their oxygen, such as social embarrassment, restricted movement and discomfort.

A small study of outpatients (n = 48) examining the psychological status of people with severe COPD on LTOT (mean age of 57 years) found that most of the study participants had depression (79% using the Becks Depression Inventory [BDI]), and did not believe in the effectiveness of the long term oxygen therapy (Borak, Sliwinski, Piasecki, & Zielinski, 1991). DiMatteo, Lepper and Croghan (2000) conducted a meta-analysis of 12 studies about depression and treatment adherence (although not in COPD) and found depressed people were three times more likely to be non-adherent with recommended treatment (odds ratio [OR] of 3.03 95% CI, 1.96-4.89). A cross-sectional self administered study of 276 COPD patients (mean age 71 years) examining factors associated with non–adherence to medication regimes, revealed through multivariate analysis that how a person is feeling and secondly getting confused about their medications are important independent predictors of non-adherence (p values < 0.01) (George, Kong, Thoman, & Stewart, 2005).

Pulmonary Rehabilitation

Smoking cessation, optimising function and quality of life with medications and pulmonary rehabilitation are principal goals of COPD management. Pulmonary rehabilitation involves a spectrum of interventions including patient assessment, exercise training, education, nutritional interventions and psychosocial supports. These non-pharmacological interventions address the primary and secondary impairments associated with chronic obstructive pulmonary disease. Pulmonary rehabilitation has become recognised as cornerstone in the holistic management of patients with chronic obstructive pulmonary disease (Nici et al., 2006). A Cochrane systematic review of 31 randomised control trials (RCTs) by Lacasse, Goldstein,

Lasserson and Martin (2006) confirms rehabilitation significantly relieves dyspnoea and fatigue, increases exercise capacity, improves emotional function and enhances a patient's sense of control over their condition. In essence pulmonary rehabilitation has the ability to break the downward cycle of deconditioning and its associated costs shown earlier in Figure 2.1.

Patient-centred COPD management

The CHS nursing team consists of specialist and generalist nurses who provide in the main, home nursing management for patients with complex often chronic health needs including chronic obstructive pulmonary disease. CHS nurses work collaboratively with the CHS multidisciplinary team to support the intended patient outcomes. The type of respiratory services provided include pulmonary rehabilitation, smoking cessation, short and long term home oxygen therapy; home visits for support, information about medications, nutrition, dyspnoea management strategies and the provision of palliative care. Figure 2.2 shows the make-up of CHS home services for respiratory patients.

In day to day practice CHS nurses communicate with the CHS multidisciplinary team, general practitioners and the wider primary care practice team reporting, referring and transitioning care and clinical information in a timely manner to support effective and co-ordinated care. CHS nurses make use of a range of developed assessment tools (for example, the Braden pressure risk assessment, Falls risk assessment and the Mini Mental State Examination [MMSE] which screens for cognitive impairment), to guide appropriate interventions and referrals.

There remain opportunities for improved holistic (physical and psychological) assessment and management. Research from the United Kingdom, United States and Canada has shown that communication problems are common and that most patient complaints are linked with poor communication (Roberts & Bucksey, 2007; Simpson et al., 1991). Additionally it has been highlighted in a recent government paper: *Meeting the Needs of People with Chronic Conditions* (National Health Committee, 2007), that people in New Zealand want better co-ordination of services, clearer information about their conditions and a recognition of their life and culture.

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                    │   Current CHS services
                    │   and personnel
                    │   available in the home
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Figure 2.2: Community Health Service home services for respiratory related conditions

Current CHS services and personnel available in the home

The chart branches into four categories: Home Care Equipment, Episodic Home Health Care, Chronic Home Health Care, Palliative Home Care.

Home Care Equipment

Equipment
Oxygen
Ventilators
Non-invasive ventilation
Mobility equipment
Suction
Nebulisers

Personnel
Registered Nurses
Physiotherapists
Occupational Therapists (OTs)

Episodic Home Health Care

Services
Assessment
Treatment
Patient education
Symptom management
Referral
Pulmonary rehabilitation
Personal care/home help

Personnel
Registered Nurses
Physiotherapists
OTs
Dieticians
Health care assistants (HCAs)
Social workers

Chronic Home Health Care

Services
Assessment
Monitoring

Personnel
Registered Nurses

Palliative Home Care

Services
Assessment
Symptom management
Personal care
Home help
Caregiver support

Personnel
Registered Nurses
HCAs

Figure 2.2: Community Health Service home services for respiratory related conditions

In keeping with contemporary models of patient-centred care, the code of conduct and the unique nature of the home care setting, specific care goals should be negotiated by patients and families in partnership with the registered nurse. The home environment in which the district nurse practices can be favourable to the development of a therapeutic relationship. Miller (2002) explored the literature examining skills required for effective communication with older people and identified that while a person is receiving nursing care in the home it allows a person to have greater control of the situation because the nurse is the visitor. Furthermore home care can be used to meet societal goals to reduce health care costs such as hospitalisation.

Patient-centred communication can be described as communication that is informative, actively encourages patient participation and questions and responses address the physical, social and emotional issues (Seidel, Ball, Dains, & Benedict, 2006). A literature review by Maquire and Pitceathly (2002) found that patient-centred communication resulted in patient problems being identified more accurately. Additionally, patients reported more satisfaction with their care, were less distressed, less susceptible to depression and anxiety and more likely to adhere to treatment and follow behavioural change advice.

However, patient participation within the healthcare setting involves a number of complex ethical considerations. Crumbie (2000) considered how ethical principles can help to inform decisions about the level of passivity or activity patients should have in healthcare. If a nurse utilises the principle of autonomy, then each patient has the right to information about their diagnosis and treatment given in an appropriate and comprehensible way. Paternalism results in the patient taking a passive role in their health care. In relation to beneficence and non-maleficence a patient who is actively participating in the process of healthcare needs to be fully informed of the consequences of treatment decisions. Finally, justice relates to how the just distribution of limited resources and patient participation can be sought through consumer advisory groups. These ethical principles dictate that patients should be regarded as partners and the nurse has a responsibility to engage patients in this way.

Impact of Depression

Depression is characterised by alterations in mood, thinking and activity, considerable enough to cause impairment in a person and / or social functioning. Evidence-based clinical guidelines highlight that depressive disorders are common (major depressive disorder rate in NZ estimated at 16%), and under recognised. Effective treatments for depression are available and consist of anti-depressants, psychosocial and psychotherapeutic interventions. However, resources need to be in place in practice to support effective diagnosis, treatment, and follow-up (New Zealand Guideline Group [NZGG], 2008; United States Preventive Services Task Force [USPSTF], 2002).

Studies show depression in COPD is significant and associated with increased hospital admissions, increased length of stay, reduced functional status, poor quality of life, poor treatment adherence and premature death (Cully et al., 2006; de Voogd

et al., 2009; Fan et al., 2007; Gorecka et al., 1997; Gudmundsson et al., 2005; Kunik et al., 2005; Kim et al., 2000; Ng et al., 2008; NOTT, 1980). Kim et al., Kunik et al., Lacasse et al. (2001) and Lewis et al. (2007) concluded that there is good evidence that depression is often under recognised and undertreated in patients with COPD on long term oxygen therapy. Cully et al. comment that because of the impact of depression on the lives of people with COPD, working to routinely screen, refer and treat depression has the potential to positively affect the quality of care and patients quality of life.

Screening for depression in practice

Depression assessment measures identify the possibility of depression and provide an indication of the severity of symptoms. By recognising depression in this patient group, more timely access to appropriate interventions could be achieved and result in enhanced quality of care and potentially less impact from depression. Although community nurses should gauge depression (MOH, 2001b) as part of routine health status monitoring, at the time of this research the nursing service where this research was conducted are not using a specific depression screening tool. In the recently published National Health Service (NHS) best practice guidance for long term conditions (Department of Health, 2009) the percentage of people screened for anxiety and depression is listed as a quality indicator of community services. NZ does not have such a standard. The United States Preventive Services Task Force (2002) clinical guidelines concluded there is insufficient evidence to recommend for or against the routine screening with standardised questionnaires for depression in primary care. However, targeted screening is recommended by recently developed New Zealand guidelines in primary care for "high risk" patients, for example those with chronic diseases, chronic pain or social isolation (NZGG, 2008).

Kunik et al. (2008) showed that providing targeted interventions can be effective in addressing depression symptoms. Throughout 2002-2005, Kunik and colleagues conducted an interventionist RCT involving 238 COPD patients with a mean age of 66 years and a mean FEV1 of 46% of predicted and who had been treated for moderate depression for one year prior to study entry. The groups were split into two, 120 participants received eight COPD education sessions and 118 received eight cognitive behavioural therapy (CBT) sessions. Depression was assessed over the follow-up period of 12 months using the BDI-11. The results showed significant improvements with both education and CBT (p values <0.005). Mean BDI-11 for education group at baseline was 21.12 (standard deviation [SD] 12.09) equal to

moderate depression, and at the end of treatment 14.54 (SD 13.47) equal to mild depression For the CBT group pre treatment was 23.44 (SD 12.49) and post treatment 14.19 (SD 13.69).

Coventry and Hind (2008) completed a systematic review and meta-analysis to estimate the effect of pulmonary rehabilitation on anxiety and depression (using the BDI-11) in patients with mainly moderate to moderately severe COPD (according to FEV1). Three studies involving 269 participants showed that comprehensive pulmonary rehabilitation (up to 3 sessions per week involving exercise, education and psychosocial support), was appreciably more effective than standard care (out-patients or primary care, with or without education) in reducing depression (standardised mean difference [SMD] = -0.58, 95% CI: -0.93 to -0.23, p=.001).

In end-stage or very severe COPD a person is likely to be mainly housebound, breathless at rest and report marked breathlessness with activities of daily living i.e. dressing and undressing. Hill, Goldstein and Lacasse (2008) review of anxiety and depression in end-stage COPD highlighted that feelings of depression may be precipitated by the loss and grief linked with the disability of chronic obstructive pulmonary disease. Agusti and Soriano (2008) reviewed depression and other additional systemic effects of severe COPD, including weight loss, increased risk of cardiovascular disease and osteoporosis. These authors conclude screening and appropriate management of these multi-system effects seen in COPD is necessary to provide optimal care and improve quality of lives for people with this long term condition.

What the COPD guidelines say about assessing for depression

Monitoring in COPD can be described as periodically observing, assessing and/or testing and recording aspects of a patient's physical and mental condition. The processes regarding the recognition and treatment of depression are given little significance in the COPD medical and treatment guidelines (McKenzie et al., 2007; NIH, 2007) even though the research indicates depression is a significant issue in chronic obstructive pulmonary disease. Van den Bemt et al. (2008) reviewed 18 clinical practice guidelines which indicate evidence to support the recommendations for monitoring patients with COPD are lacking. These authors discuss that it may be due to the limited number of well designed trials on this topic. Concluding data should be collected on things such as the significance of regular lung function testing and

the effectiveness of monitoring dyspnoea and depression; and evaluated for the clinical benefits for the patient like reduction in symptoms and improved quality of life.

Summary

COPD is a multifaceted long-term condition of different pathophysiologies and clinical presentations, incorporating pulmonary and extra pulmonary effects. The multi-system effects generally result in significant impairment and disability for those with chronic obstructive pulmonary disease. Ongoing assessment and monitoring, supported by effective pharmacological and non-pharmacological interventions are needed to optimise the quality of life for people with chronic obstructive pulmonary disease.

In practice CHS nurses regularly see patients with COPD on LTOT for assessment, clinical intervention, education, support and the provision of equipment at home. A nurse will work with the CHS multidisciplinary team and refer to other services and providers as appropriate to ensure suitable and timely interventions are provided for patients. Currently CHS nurses do not make use of a specific depression screening tool. Although depression should be gauged as part of the holistic nursing assessment, research has found that depression is often not recognised or treated.

Regular monitoring of the physical and psychological impacts of COPD allows clinicians to recognise when a person's health status declines so they can intervene appropriately. With the reported high prevalence and impact of depression in COPD, formal assessment for depression may well be useful as part of standard practice to improve the quality of the assessment and care provided for depression in this patient population. The evaluation of the benefits for the patients of the routine assessment of depression is an identified area for future research. The next chapter presents the findings of the literature review carried out to position the question and inform the design.

CHAPTER 3 – LITERATURE REVIEW

This chapter presents a review of the critical points regarding the current knowledge of the overall depression prevalence in chronic obstructive pulmonary disease (COPD). A survey and critique of the literature regarding depression rates for patients with COPD on long term oxygen therapy (LTOT) is provided. The rationale for, and design of this study emerged from these research findings and the current body of knowledge available on depression prevalence for COPD patients on long term oxygen therapy.

METHOD

Search strategy

A literature search and critical appraisal of collected studies were conducted. The following abstract databases Pub Med; PsycINFO; Cumulative Index of Nursing and Allied Health Literature (CINAHL); and the Cochrane Library were searched. The following keywords (MeSH terms) searched were: 'depression' and 'chronic obstructive pulmonary disease' and 'prevalence' and 'oxygen'. Due to the limited number of 'hits' (n=19) a second search was conducted using the terms 'depression' and 'prevalence' and 'chronic obstructive pulmonary disease'. English language was the only limiter set for the database searches. This latter search yielded 82 articles. In addition, studies were identified from the reference lists of the articles yielded. Overall 118 abstracts were read that potentially related to this study, from which 27 studies were appraised. This literature review includes the appraisal of primary studies and systematic reviews on the prevalence of depression in chronic obstructive pulmonary disease.

Critical appraisal

Each of the articles was examined and data were extracted from the full text copy of the studies for review. Information obtained and questions for each study included the findings, instrument used to diagnose or screen for depression, COPD diagnosis criterion, depression instrument diagnosis or risk criterion, recruitment strategy, study setting, sample size and profile. Overall, the quality of the primary studies is generally good and provides evidence that depression is a common mental disorder in chronic obstructive pulmonary disease. All the studies included for appraisal used depression measurement instruments that were developed and validated in the English language. Overall there was a significant lack of uniformity in methodology and

design, resulting in variable prevalence rates. Particularly, different depression assessment tools and cut of scores were used to define depression and these affect baseline prevalence rates. Other methodological issues such as sampling bias (convenience sampling), and limited reporting of some aspects of the clinical and demographic profile of the responders and non-responders (e.g. oxygen use, ethnicity) limit the validity and generalisability of the results to the New Zealand (NZ) practice context. The use of variable COPD diagnostic criteria and disease severity inclusions across studies impacts on attempts to compare different studies.

RESULTS AND DISCUSSION

Overview of the literature

The literature review showed the earlier COPD depression prevalence studies were generally descriptive (Jones, Baveystock, & Littlejohns, 1989; Light, Merrill, Despars, Gordon, & Mutalipassi, 1985), more recently systematic reviews of these prevalence studies have been published (Maurer et al., 2008; van Ede, Yzermans & Brouwer 1999). The primary studies have had similar approaches in collecting data. Generally convenience sampling and the use of a range of specific diagnostic or screening instruments have been used to measure depression rates in chronic obstructive pulmonary disease. Some studies measured the prevalence of anxiety as well as depression (Funk, Kitchener, Burghuber, & Hartl, 2009; Lewis et al., 2007). Recently population-based approaches have been used to establish the prevalence of depression and other co-morbid psychological and physical conditions (Barr et al., 2009; Scott & Williams, 2007). The studies have been conducted in a number of countries. There were no identified studies conducted New Zealand.

Some well published international COPD experts are co-researchers in the more recent studies (Barr et al., 2009; Lacasse, et al., 2001). However, there is not one prolific COPD researcher who has extensively examined depression prevalence in COPD and more specifically in COPD patients on long term oxygen therapy. Overall there is a lack of research about depression prevalence for patients with COPD on long term oxygen therapy. The literature, although limited, does indicate a high prevalence of depression in COPD LTOT patients (Lacasse et al.; Lewis et al., 2007).

Systematic reviews

Systematic reviews of the prevalence of depression in older people, people with COPD and other disease populations, positions the issue of depression in COPD and shows the reported depression prevalence rates vary considerably. A review of

depression in older adults (55+) in primary care, reported the prevalence range from 34 studies (involving over 40,000 participants from different countries) between 0.4-35% (Beekman, Copeland, & Prince, 1999).

A systematic review specifically investigating the prevalence of depression in COPD by van Ede et al. (1999) included 10 studies (860 participants) conducted in the 1980s and 1990s. van Ede et al. found the prevalence range for depression in people with moderate to severe COPD was 7-42%. This systematic review had a comprehensive search strategy focusing specifically on depression prevalence in people with chronic obstructive pulmonary disease. The studies were reviewed by three authors and rated according to five methodological criteria: 1) response rate of >80%, 2) control group matched for age and sex, 3) random selection of patients, 4) prevalence of depressive disorder detectable and, 5) exclusion of important physical disease other than chronic obstructive pulmonary disease. In the review four of the studies were case-control studies comparing results between COPD patients and controls. All of these case-control studies reported an increased prevalence of depression among patients with COPD, but only two of the study's results were statistically significant. The two studies that showed statistically significant differences involved 285 patients on LTOT with severe chronic obstructive pulmonary disease.

A later review by Solano, Gomes and Higginson (2006) of 64 studies focused on depression in advanced acquired immune deficiency syndrome (AIDS), COPD (150 COPD patients), heart disease, cancer and renal disease, established the prevalence of depression in severe COPD ranged from 37-71%. Solano et al. found the high rate of depression seen in severe COPD is comparable or greater than that of the other advanced disease.

The most recent review (Maurer et al., 2008) was based on a workshop conducted by the American College of Chest Physicians, sponsored by the National Institute of Mental Health and the Alpha -1 Foundation. The objectives of this workshop were to review the current knowledge about anxiety and depression in COPD and identify unanswered questions and future research needs. Maurer et al. identified the overall prevalence of depression in stable COPD from the results of 16 outpatient studies (n=3232) ranges from 10-42%. These authors found that the risk of depression was higher (OR 2.5; 95% CI 1.2-5.4) in patients with severe COPD with the highest rates (up to 62%) in the oxygen dependant patients.

In summary these reviews of studies on the prevalence of depression in people with COPD conducted from 1982-2006 have found the presence of depression ranges from 7-79%. The latest review (Maurer et al., 2008) included overall large numbers, but only one study included LTOT patients (Lacasse et al., 2001). Eleven of the studies Maurer et al. reviewed were completed over 10 years ago and five were reviewed as part of the van Ede et al. (1999) review.

Studies that utilised depression screening or diagnostic instruments

To gain more recent information regarding the incidence of depression in people with COPD on LTOT and identify any further research opportunities a critical review of identified relevant studies conducted in the past 10 years was undertaken. Table 3.1 presents the data from these studies.

Concurring with the reviews discussed, the studies detailed in Table 3.1 highlight the continued wide range in reported prevalence of depression. Ten of the 11 studies show the overall prevalence of depression in people with confirmed COPD (by FEV1) ranges from 11-75% using self reported instruments. There are a few main factors that contributed to the variation in depression prevalence rates reported. Firstly there are factors relating to the methods used to detect people who have depression. Some studies used screening questionnaires for example the Hospital Anxiety and Depression Scale (HADS) and Becks Depression Inventory (BDI), while others used diagnostic interviews for example the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (SCID). Secondly there were factors relating to the sample. Studies included patients at different stages of disease severity. The studies that included people with more severe disease (as measured by FEV1) had higher depression rates. Studies had varying sample sizes and generally power calculations were not completed. Some studies had controls while others did not. Ethnicity was not always described. Also noted were factors relating to the studies setting and methods of data collection. Some studies used self reported instruments, some face-to-face interviews, some were postal surveys and some were conducted by phone. Where reported the non-response rates ranged from 37% to 53%. Studies were mainly single centre outpatient. The different methodological factors across studies prevent definite conclusions being made about the risk of depression and the cross-cultural and geographical variations in depression prevalence in chronic obstructive pulmonary disease.

Table 3.1: Primary studies investigating the prevalence of depression in COPD

Study	Setting	Instrument*	Sample size	Sample profile	Finding / Comment
Kim et al. (2000)	United States Outpatients Veterans Medical Centre	Self report: GDS	43 with COPD	Mean FEV1 (GOLD) moderate Mean age 69 years 100% male 86% white	39.5% had moderate-severe depression (GDS>10) Small study, all male, mostly white 47% response rate
Yohannes, Baldwin, & Connolly. (2000)	England Outpatients	Self report: GMS	137 with COPD	Mean FEV1 (GOLD) severe Mean age 73 Male 69 female 68	42% identified as clinically depressed Ethnicity not described
Van Manen et al. (2002)	Netherlands 28 general practices	Self report: CES-D	162 with COPD 359 control	60 participants had FEV1 <50% (European Respiratory Society Guidelines) Mean age 73 Male 116 female 46 Dutch population	The prevalence of depression was 25.0% compared with 17.5% in controls and 19.6% in patients with mild to moderate COPD (CES-D≥ 16) COPD participants had a 2.5 times greater risk of depression than the controls
Kunik et al. (2005)	United States Outpatients Veterans Medical Centre	PRIME-MD, & Structured Interview: SCID	1334	FEV1 not defined Mean age 65 years Over 80% male Over 60% white	80% prevalence of depression using (PRIME-MD), 65% using SCID in confirmed COPD subset group (FEV1 breakdown not provided)
Wagena, Arrindell, Wouters, & van Schayck. (2005)	Netherlands Inpatients and outpatients	Self report: BDI	118 with COPD	60 participants with severe to very severe COPD (GOLD) Mean age 57 years, 55% male	BDI >15 in 22% of participants with mild to moderate COPD compared to 37% for those with severe to very severe COPD (but p=0.09). Ethnicity not described
Cully et al. (2006)	United States Outpatients Veterans Medical Centre	Self report: BDI –II	179 with COPD	Mean FEV1 45.47% (GOLD) Mean age 66 years 95% male 80% white	BDI>19 =11%. Mean BDI 22.47 (standard deviation[SD] 9.41) FEV1 was not associated with BDI-II outcomes
Di Marco et al. (2006)	Italy Outpatients	Self report: SDS, Italian version	202 with COPD. 114 age matched controls	Mean FEV1 54% 88 participants with severe to very severe COPD (GOLD) Mean age 61 Male 155 female 47	Depression prevalence overall = 19%, 23.7% for severe COPD, 13.8% for very severe COPD (p=0.636). Distribution of depression did not reach statistical significance. Author comment: LTOT excluded as people on LTOT susceptible increased psychological impairment compared to COPD people on standard medical therapy Ethnicity not described

Table 3.1: continued

Study	Setting	Instrument*	Sample size	Sample profile	Finding / Comment
Ng, Niti, Fones, Yap, & Tan. (2008)	Singapore Outpatients	Self report: GDS	189 with COPD 2213 without	Majority had mild COPD 43.9% having moderate to severe COPD (FEV1 <80% GOLD staging) 55 years and over (37% 55-64 and 44% were 65-75 years) 64% COPD population female Chinese population	COPD people depressed =22.8% (12.4% for those without COPD) GDS>5=depressive symptoms. (OR 1.86 95%CI 1.25-2.75). Severe COPD = increased depressive symptoms. But small numbers with FEV1 <50% (only 9.5%). Depression was associated with worse health & functional status.
Funk et al. (2009)	Austria Inpatients and Outpatients (Vienna primary hospital)	Self report: HADS	122 with COPD	Mean FEV1% (GOLD) 44.5 ± 19.3 Mean age 65 Male 68 female 54	Depression=52% (HADS score 8 or greater).Depressive symptoms were independent of gender (51% of the men; 52% of the women). FEV1% was lower in patients with depressive symptoms (37.0 ± 15.2) than patients without (52.5 ± 20.0), mean difference-15.5, 95% CI-21.8-9.2; p <0.001. Ethnicity not described
LTOT Studies	**Setting**	**Instrument***	**Sample size**	**Sample profile**	**Finding / Comment**
Lacasse et al. (2001)	Canada Outpatients	Self report: GDS (translated to French)	109 with COPD 105 on LTOT	Mean FEV1 34% (GOLD) severe, 96% on LTOT Mean age: 71 Male 63 female 46 Average 19 months on LTOT	Total depression rate=75% 57%; (95% confidence interval [CI]: 47-66) showed significant depressive symptoms (GDS≥ 11-19); in addition 18% (CI: 12-27) were severely depressed (GDS ≥ 20) Ethnicity not described. Consent obtained by usual visiting nurse or therapist. Response rate 62%
Lewis et al. (2007)	England Outpatients	Self report: HADS	114 with COPD 57 on LTOT	All severe (GOLD) COPD. COPD group mean FEV1 34%, age 67; LTOT group mean FEV1 32%, age 70 Male 31 female 26 Exclusion criteria LTOT<3months Average time on LTOT 19 months	37% of the not on LTOT=depression 33% on LTOT=depression (HADS ≥ 11) p value 0.77 = not significant due to similar depression levels between the two groups Ethnicity not described. Power calculation completed. Postal survey=response rate 63%

*GDS= Geriatric Depression scale. HADS=Hospital anxiety and depression scale. BDI=Beck Depression Inventory BDI-11=second edition. SDS=Self rated depression scale. GMS=Geriatric Mental State schedule. CES-D=Centres for Epidemiologic Studies Depression scale. SCID=Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. PRIME-MD=Primary Care Evaluation of Mental Disorders. GOLD= Global Obstructive Lung Disease FEV1% of predicted grading criteria.

The Kunik et al. (2005) study had the highest overall depression prevalence of the studies in Table 3.1. Eighty percent of the initially phoned screened participants were found to have depression. In the subset of COPD patients (confirmed by spirometry) 65% were diagnosed using SCID with anxiety and/or depression. The authors made the comment that the study's population group are known to have higher prevalence of anxiety and depression than the general population. But of note, only 31% of this population were receiving treatment for anxiety or depression at the time of the study.

Relevant to practice and this current study there remains a lack of published results on the prevalence of depression in COPD patients on long term oxygen therapy. In particular lacking is of trials of depression in NZ COPD and/or COPD LTOT populations. Only two of the trials described in Table 3.1 included LTOT patients (Lacasse et al., 2001; Lewis et al., 2007). These studies do draw attention to the potential scale of depression in this COPD population but to date the overall numbers of patients described in studies as on LTOT is small and this limits generalisability of the research.

The overall reported prevalence could in fact be lower than the number of actual cases because of sampling bias (convenience sampling) and under diagnosis. Patients with high levels of depression may be less likely to consent to participate in studies. Furthermore, one of the challenges in measuring the occurrence of depression in COPD patients could be related to the large overlap between the symptoms of depression and COPD (van Ede et al., 1999). Both are associated with symptoms such as increased fatigue, sleep and appetite disturbances and trouble concentrating (APA, 2000; DiMatteo, Lepper, & Crogan, 2000; NIH, 2007). Lacasse et al. (2001) reported that by using the GDS they were able to address this overlap of symptoms between depression and chronic obstructive pulmonary disease. They explained the GDS was specifically developed to be used with well and unwell older adults and that it minimises questions about health concerns. A GDS score of ≥ 11/30 is associated with a sensitivity of 84% and a specificity of 95% for the diagnosis of significant depressive symptoms; a score of ≥ 20/30 indicates severe depression.

Lacasse et al. (2001) make the point that whether LTOT, in addition to COPD itself, contributes to depression is unknown. These authors did not find any clear relation between GDS scores and the length of time a person had been on long term oxygen therapy. The early landmark LTOT trials (MRC, 1981; NOTT, 1980) were conducted before the development of now frequently used disease specific quality of life

questionnaires that measure important changes in quality of life and emotional function. Since these landmark trials demonstrated survival benefits using low flow domiciliary (home) oxygen in hypoxemic patients, LTOT has become the standard of care. This creates no further opportunity to randomise hypoxemic patients with COPD to receive or not to receive LTOT to measure the effectiveness of oxygen on quality of life.

Lewis et al. (2007) found that patients with severe COPD on LTOT do not differ significantly in prevalence of symptoms of depression from those with severe COPD who are not on long term oxygen therapy. Lewis et al. considered that perhaps by relieving breathlessness or improving exercise tolerance, LTOT may lesson depressive symptoms. However, this remains unproven and the relationship is complex.

Population based studies

Scott and Williams (2007) carried out a population study in Canada of mental disorder prevalence through face-to-face and phone interviews of 36,984 household residents. Scott and Williams utilised the World Mental Health Composite International Diagnostic Interview: a fully structured psychiatric diagnostic interview. One or more respiratory illnesses were reported by 4,448 of the research participants; 1,958 specifically identified they had COPD (chronic bronchitis or emphysema). The prevalence of major depression for chronic bronchitis was 8.7% (CI 6.8-10.7) and emphysema 7.5% (CI 4.7-10.2) compared to no respiratory condition 3.6% (CI 3.3-3.8). Their study relies on self-reported respiratory status, rather than a confirmed diagnosis through FEV1 measurement. Scott and Williams results show a higher incidence of depression in people with COPD compared to people without respiratory conditions. The percentages of depression in COPD are quite low compared to other study results that reported on the prevalence of depression in people with confirmed (by FEV1) chronic obstructive pulmonary disease. These authors concluded that a possible reason for the lower overall estimates is because this is a population study and therefore selection bias is reduced, signifying selection bias in clinical studies may influence prevalence estimations.

A telephone survey in a national sample of 1003 patients with COPD revealed the prevalence rate of depression as 37% (p = <0.001). The sample were drawn from households where one or more persons were reported as being diagnosed with COPD (FEV1 not described). In this survey patients were asked if they had been

diagnosed with COPD and then additionally they were asked about a range of physician diagnosed co-morbid conditions, depression being one. The published report does not outline the specific questions used but state the questions were developed by a panel of experts, including physicians, patients and representatives from COPD organisations (Barr et al., 2009). This study like the Scott and Williams (2007) study was a direct patient survey and a national sample. The key difference is that the sample were drawn from a known COPD population. This could indicate rather than a study bias, for patients diagnosed with COPD a co-morbid diagnosis of depression is common.

SUMMARY

To date the association between COPD and depression remains unclear as depression prevalence is significant across a broad range of populations. The limited research on the prevalence of depression in COPD LTOT populations, including NZ and the known impact of depression on people with COPD provide the rationale to obtain base line NZ information. Depression prevalence rates in COPD are statistically and clinically significant. The studies discussed in this chapter although of good quality show heterogeneity in the prevalence rates of depression in chronic obstructive pulmonary disease. Studies have included various depression screening and diagnostic tools, COPD diagnosis criterion, have often not captured important variables like disease severity (including whether patients were on LTOT), or ethnicity of the study participants.

This literature review highlighted a number of key considerations in the type of and way data are collected that informed this point prevalence study to improve the applicability, reduce bias and improve potential non-response rates. The COPD diagnosis is clearly defined. People on LTOT for conditions other than COPD are excluded. The depression criterion also clearly described. People can be described by different levels of depression and whether they are being treated for depression at the time of the study. The use of a self-reported depression assessment tool that is validated for use in the NZ primary care settings was relevant to this study's setting. Selection bias and generalisability is improved by sampling and describing the total District Health Board COPD LTOT population (i.e. by age, gender and ethnicity) in a large urban area. To improve the response rate in this study, having a methodology that made it easy and safe for this population to participate if they would like was important. The next chapter focuses on the methodology and study design for this prevalence research.

CHAPTER 4 – STUDY METHODOLOGY AND DESIGN

An observational point prevalence study was conducted to establish baseline New Zealand (NZ) information on the prevalence of depression amongst people with chronic obstructive pulmonary disease (COPD) on long term oxygen therapy (LTOT). Chapter 4 provides an account of and rationale for the method and materials employed for this study. An overview of the aims and objectives is provided, followed by an explanation of the background and rationale to the study's methodology and design. The main focus of the chapter relates to the methods of data collection and analysis.

Aims and objectives

This study's primary aim was to determine the prevalence of depression amongst people with COPD on LTOT in a large urban area in NZ. The objectives were:

- to describe the characteristics of depressed and non-depressed people (i.e. ethnicity, age, gender, disease severity), thereby improving understanding about the occurrence and variation of depression prevalence for NZ people with COPD on long term oxygen therapy;
- to inform the introduction of validated depression screening tool as standard in practice;
- to inform future service provision for COPD LTOT patients in the community; and
- to provide new knowledge of the prevalence of depression in the NZ COPD LTOT population and add to the total body of knowledge on the prevalence of depression in chronic obstructive pulmonary disease.

Understanding the prevalence of depression in COPD patients on LTOT will highlight and potentially enhance health professional's assessment and interventions for individuals with symptoms of depression. At service level, it potentially will positively impact the type and level of services provided to this population group.

BACKGROUND TO THE METHODOLOGY AND DESIGN

Observational research foundations

Epidemiological health research is concerned with the description of health-related states of populations through the collection of data related to the health and incidence, distribution and determinants of disease in populations with the aim of improving health. Epidemiology research dates back to Hippocrates 400 BC, who hypothesised that disease might be associated with the environment. Modern health

epidemiology has been led by physicians such as Dr John Snow who is famous for investigating the causes of the 19th century cholera epidemic and Doll and Hill (1954) who led the British Doctor's Study that provided strong statistical evidence to support the notion that cigarette smoking causes lung cancer.

Epidemiologists make use of observational study designs to examine the frequency and distribution of illness. Observational studies have a role in research into the patterns of disease and the benefits and harms of medical interventions. This information is then often used to investigate causes of disease. Observational designs include cohort, case-control, case-report, cross-sectional and ecological study designs. High quality observational studies can produce trustworthy evidence of intervention effects and can be more clinically relevant than randomised controlled trials (RCTs) (i.e. better generalisability or applicability) and include populations of interest to clinicians (Lu, 2009). This study used a cross-sectional study design to examine the prevalence of depression amongst people with COPD on long term oxygen therapy.

Framework

The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement details a 22 item check list for cross-sectional study design that serves as the now widely used framework to guide what should be included for accuracy and comprehensiveness in the reporting of this type of observational research (Von Elm et al., 2007). The check list which is freely available on the STROBE website (http://www.strobe-statement.org) guided the content of the title, abstract, introduction, method, results and discussion for this study.

Using this framework

There were five key factors considered as part of ensuring this study's methods were valid and the findings useful locally and elsewhere. Firstly, relating to the overall methodology chosen to answer the research question; a cross-sectional design was used as it is the best way to determine prevalence of a health problem. A cross-sectional study aims to describe the connection between disease and other factors of interest as they exist in a particular population at a point or period in time and may be used as a basis for health policy decisions (Mann, 2003). Although this type of study identifies the existence of health problems at a point in time it does not identify cause-and-effect relationships. Prevalence is significant to the clinician because it influences the likelihood of a certain diagnosis and the predictive value of an investigation. In prevalence studies the participants are assessed at one point in time

to establish whether they were exposed to an intervention or risk factor and whether they have an outcome (Lu, 2009).

Secondly, the generalisability and external validity of the data in the NZ and wider health context were considered. This prevalence study sampled the total COPD LTOT population in a large urban region of NZ. Describing the population characteristics will enable those appraising this research to assess its applicability to their population of interest. The generalisability and external validity of the results is high amongst this population group in NZ, but as it is a narrowly defined population the generalisability is limited outside COPD LTOT population.

Addressing the possible reasons for non-response can improve a study's validity. If the reasons for non-response are not related to the health outcome measured and the characteristics of the non-responders are comparable to the responders, researchers are better placed to justify a modest response rate. However, response rates can be improved if the assessment is easily accessible (i.e. home might be more suitable for the elderly), conveniently timed, acceptable in length and appropriate in content for participants (Loney, Chalmers, Bennett, Roberts, & Strafford, 2000).

Thirdly, it is important to know what sample size is required to ensure the study is sufficiently powered to be statistically and clinically significant. Generally the higher the number of selected participants who are not available for measurement, the less valid the estimate is (Peat & Barton, 2005). To be sufficiently powered the response rate for this study was estimated at 61. This calculation was undertaken using a computer program (http://sampsize.sourceforge.net/iface/index.html). The sample size calculation assumed a precision of 5% and depression prevalence of 33% taken from the results of the study by Lewis et al. (2007) and this study's total population (n=73) size. The study was not powered to consider differences between subgroups.

The fourth point considered was addressing the potential sources of bias in this study. The self-administered depression questionnaire was left with some of the participants to complete so others could have filled it in on their behalf. Additionally, using a depression questionnaire that is freely available access (i.e. on-line) potentially allowed people to alter their scores to try and reflect a more favourable response. These issues were addressed to some degree by statements in the consent form (Appendix 2) and information sheet (Appendix 3) such as "The Patient Health Questionnaire-9 (PHQ-9) is a screening questionnaire only and positive

results would not necessarily mean you have depression" and "I agree to my depression questionnaire results being sent to my GP YES/NO". Participant study information, support and follow-up offered were provided to fully inform and ease any concerns a person may have regarding their depression questionnaire results. However, those people that chose not to participate may have done so because of depression or because they did not want to be screened for depression.

The final key factor was to consider the measurement tools used to answer the study question. The literature review reflected a range of screening tools in existence that could be appropriately used to assess depressed mood in people with COPD. For example the Becks Depression Inventory (BDI) used in a few of the presented studies in Chapters 2 and 3 was originally developed in 1961, revised in 1978 and again in 1996 (BDI-11). The BDI is one of the most frequently used and well validated measures of the severity of depression in adolescents and adults by both researchers and clinicians, it has been validated in a range of countries, settings, languages and ethnic groups (Grothe et al., 2005). Also the Geriatric Depression Scale (GDS) has been shown to have good sensitivity (correctly identified as condition positive by a positive result) and specificity (correctly identified as condition free by a negative result) in older adults (Lacasse et al., 2001). As there were no identified NZ studies conducted using these measurement tools evidence-based guidance for this study was sought from the recently published NZGG publication: *Identification of Common Mental Disorders and Management of Depression in Primary Care* (2008) for the best tool for NZ community nurses to use for research and practice.

The short either clinician or self-administered PHQ-9 is identified in the NZGG (2008) publication as being valid and reliable in adults for identifying and assessing the severity of depression in primary care. A primary care screening tool was considered to be the best tool as community nurses provide preventative and ongoing essential home care, working to co-ordinate and support the transition of people's overall care back to the primary care practice (a person's medical home).

The PHQ-9 was developed by Spitzer and colleagues and scores the nine symptoms of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (APA, 2000) of major depression criteria as "0" (not at all) to "3" (nearly every day) giving a score range of 0-27. The recommended cut of scores for the PHQ-9 are 0-4 (none), 5-9 (mild), 10-14 (moderate), 15-19 (moderately severe), 20-27 (severe). Although there is limited data about the PHQ-9 use with COPD patients, there is a range of good

information about the assessment of depression, and use of this tool in other chronic illnesses in primary care (Maurer et al., 2008; NZGG, 2008).

Two recent studies examined the validity of the Patient Health Questionnaire-9. The PHQ-9 was compared to the BDI-11 by Dum, Pickre, Sobell and Sobell (2007) in 108 outpatient's substance abusers. Dum et al. found both tools to have good internal consistency (Cronbach's alpha reliability coefficient of the BDI-11 and the PHQ-9 were 0.95 and 0.91 respectively). Dum et al. studied substance abusers so the results cannot be directly extrapolated to COPD patients. More recently the validity and reliability of the PHQ-9 were examined in a population of elderly Dutch patients (n = 713) from 89 general practices diagnosed with diabetes and COPD without known depression (Lamers et al., 2008). Lamers et al. found that when the PHQ-9 is used as a continuous measure (representing depression severity ranges from 0-27), summing the responses to the nine questions (rather than using the scoring algorithm with a cut off point for major depressive disorder and any depressive disorder), the PHQ-9 was valid and reliable in elderly COPD and diabetic patients. The test-retest internal reliability (Cronbach's alpha) for the PHQ-9 in the COPD participants was 0.84 (n = 79). A test-retest of the summed score (Pearson's r intraclass correlations coefficient [ICC]) were also conducted in these 79 patients and was 0.90. The optimal cut of point was PHQ-9 ≥6 for any depressive disorder with a sensitivity of 95.6% and a specificity of 81.0%. Additionally, the PHQ-9 tool is simple to use taking generally less than five minutes to complete and is free for researchers, clinicians and the public to access. This current study used a score of 5 or more as an indication of depression.

ETHICS

The Central Regional Ethics Committee approved this study via the national ethics application process in July 2009 (Appendix 1). There were two key ethical considerations identified in the development of this study to address participant safety given the nature of this research. Firstly, minimisation of harm; all registered nurses assisting with this study were bound by confidentiality, professional standards and scopes of practice. They were provided with specific training by the lead researcher (supported by research supervisor) about the information and consent process and about the self reported depression and demographic questionnaires. The nurses were advised that where a patient's depression questionnaire (PHQ-9) results indicated depression they would inform the patient about the results and develop a plan in partnership with the patient, including advising the person to see their general practitioner (GP). The GP was only informed of the PHQ-9 results with

the patients consent (Appendix 4). The participant consent form and information sheet (Appendix 2 and 3) cover the participant information regarding this issue.

Secondly, Treaty of Waitangi obligations; the study aimed to incorporate Māori (the indigenous people of NZ) to generate useful data without imposing an unethical burden on Māori. Hospital clinical records showed Māori were over 20% of the COPD LTOT population at the time of the study. Consultation with Māori resulted in support being offered to Māori participants by Whanau Care Services registered nurses whose role is to provide advocacy and support to Māori Whanau (family) and providers working with Māori (Appendix 5).

THE METHODS

Study population

In September 2009 the cross-sectional study among the total population (n=73) of COPD patients on LTOT registered to the District Health Board (DHB) Community Health Service (CHS) was conducted. Although ethics approval was granted in July 2009, data collection was delayed until September so the impact of winter colds and flu (significantly the impact of the 2009 swine flu outbreak) did not limit patient participation or place an increased burden on the community nursing staff coping with high winter workloads and staff illness.

The participants were outpatients with a clinical diagnosis of COPD (generally confirmed by an FEV1 ≤ 80% as per the Global Obstructive Lung Disease (GOLD) guidelines (NIH, 2007), who had been on LTOT for more than three months. The researcher set the participant criteria of being on LTOT for at least three months to allow time for people to adjust to a new treatment (LTOT). This timeframe was in line with the Lewis et al. (2007) study that examined depression in a similar patient population. Recruitment for this study involved four phases:

1. Identification of COPD patients on LTOT prior to June 2009.
2. Collection of baseline data from hospital records on all patients who meet the inclusion criteria. These data extracted on all patients were used to determine the representativeness of the responders.
3. All patients who meet the inclusion criteria were initially phoned by the principle researcher (generally known to the patients) to ask if they consented to a home visit (usual care setting for this CHS patient group) by their primary CHS nurse or the nurse researcher to receive information about participating in the study.

4. The CHS primary nurse or the nurse researcher visited the patients who had agreed to a visit to deliver the information, consent forms and questionnaires for completion.

Data collection and measurement instruments

Base-line demographic (age and gender) and clinical information (COPD diagnosis, COPD admissions and oxygen prescription details) were obtained from hospital records on the DHB COPD LTOT population. The participants were given two short questionnaires for completion, the questionnaire developed for this study (Appendix 6) and the Patient Health Questionaire-9. The nine questions of the validated PHQ are listed in Appendix 7. The developed questionnaire contained additional demographic questions about ethnicity, employment and whether they lived alone or not and clinical information about COPD treatment (LTOT usage, portable oxygen and pulmonary rehabilitation) and any depression history and treatment. Tables 4.1 and 4.2 lists all the demographic and clinical variables collected from the hospital records and the questionnaire developed for this study.

Table 4.1: Demographic variables by name, description, values and type

Variable name	Variable description	Values	Variable type
Age	Age at recruitment	In years	Continuous
Ethnicity	Ethnic status	NZ European Māori Pacific Asian Other *	Nominal
Gender	Gender	Female Male	Nominal
Employment	Employment status at recruitment	As per description*	String
Living situation	Lives alone	Yes No	Nominal

*asked to describe

A number of factors guided the data collected for this study. The Treaty of Waitangi guides the inclusion of ethnic status. This research aims to incorporate Māori participants to provide relevant information for practice. Capturing the details (i.e. age, gender, FEV1 and LTOT prescriptions) of the non-responders and responders provides an overview of the population studied that other people examining or using the research can relate to and consider its relevance to different populations.

The participants were asked whether they were currently being treated for depression but were not asked to expand on the type of treatment they were receiving. The researcher did not consider the inclusion of additional questions about

the type of depression treatment a person was receiving added value to the aims of this study. For the participants, asking extra questions about medications and counselling may have been more inconvenient in terms of time to taken to complete the questionnaires and may have been perceived as more personally invasive.

Table 4.2: Clinical variables by name, description, values and type

Variable name	Variable description	Values	Variable type
FEV1	Last recorded FEV1	% of predicted	Continuous
LTOT prescription	Actual hours prescribed oxygen	In hours	Continuous
MonthsO2	Length of time on oxygen	In months	Continuous
LTOT usage	Actual hours uses oxygen per day	In hours	Continuous
Portable oxygen use	Portable oxygen	Yes No	Nominal
Pulmonary Rehabilitation	If completed	Yes No	Nominal
Pulmonary Rehabilitation	Time since completion	Time in months	Continuous
Hospital admissions	Number in previous 12 months	Number	Continuous
Length of stay	Total length of stay in days in 12 months	Number	Continuous
History of depression	Told by a health professional	Yes No	Nominal
Depression treatment	Current treatment	Yes No	Nominal

The literature and policy reviewed as background to this study also influenced the type of data collected. For example smoking status was not included, as it is a contraindication for the prescription of LTOT in NZ (MOH, 2001a) and it was considered that inclusion of the information may be perceived negatively by participants. Living alone and employment status were asked about as these socio-demographic variables have been associated with depression (Lewis et al. 2007). The decisions to use the PHQ-9 and extend the data collected to include hours of oxygen usage, hospital admissions, pulmonary rehabilitation, ethnicity and availability of portable oxygen; over and above the only two similar studies published at the time of this study (Lacasse et al., 2001; Lewis et al., 2007) described in Chapter 3, were made to provide more meaningful information for local practice.

Procedure

A pre-test was conducted involving two people to determine the ease and suitability of the developed questionnaire and the Patient Health Questionaire-9. As no changes were required and the two people involved had fully consented their data were included in the study.

Both questionnaires were completed by the study participants in their homes, either at the time of delivery or at their own convenience. The completed questionnaires were either collected by the CHS primary nurse or returned by the participant within two weeks by post (stamped envelope provided) to the researcher for scoring and analysis.

Data Analysis

Data analysis was guided by Peat and Barton (2005). The Statistical Program for the Social Sciences (SPSS) version 16 programme was used for all statistical analyses. Tests for normality were applied. The information collected was put into an Excel spread sheet, cleaned and exported to SPSS. A five step analysis plan was undertaken. The coding sheet for the data analysis is given as Appendix 8.

Step one involved describing the total COPD population demographically and clinically, using descriptive statistics of measures of central tendency (mean, median, mode and frequency) and measures of dispersion (standard deviation, inter-quartile range and range).

Step two involved describing the additional clinical (i.e. oxygen use, pulmonary rehabilitation) characteristics of the respondents using similar statistics to step one.

Step three compared the baseline characteristics of the respondents and the non-responders using inferential statistics such as chi square, and Fisher exact test for nominal variables, and *t*-test or Mann-Whitney *U*-test for continuous variables depending on the distribution of data.

Step four determined the prevalence of depression. The prevalence of depression was defined as the population of depressed patients (PHQ-9 score of 5 or more) identified among the total of patients surveyed (95% confidence intervals [CI]).

Step five determined differences and relationships between depressed and not depressed participants, using inferential statistics such as Spearman's correlations and Mann-Whitney *U*-test.

In summary the research was designed and carried out in all stages to generate rigorous and valid results. Particular care was taken to ensure the process was safe for people. The following chapter presents the findings.

CHAPTER 5 – RESULTS

This chapter presents the findings. It commences with a description of the demographic and clinical characteristics of the population of patients with chronic obstructive pulmonary disease (COPD) on long term oxygen therapy (LTOT) for a minimum of three months under the care of Capital Coast District Health Board (C&C DHB), as at September 2009. The findings of the point prevalence study of depression in the sampled population are then presented. In these analyses, statistical significance was set at p value ≤ 0.05.

Study population

The total population of 73 people with COPD on LTOT were contacted for verbal consent to receive the information and questionnaires needed to participate in the study. Three people were excluded due to acute illness and being in hospital during the data collection period, five declined to participate and two did not return their questionnaires. For the present study, baseline data from the total population of 73 were used to compare the characteristics of the responders (n=63, 86%) and all those who did not complete the questionnaires (referred to as non responders) (n=10, 14%).

PATIENT CHARACTERISTICS

Overall descriptions

The baseline demographic and clinical characteristics collected from hospital records (age, gender, FEV1, oxygen [o2] prescription [Rx] in hours per day and date of commencement) of the total population are shown in Table 5.1. There were no statistically significant differences in the baseline characteristics for the responders and non-responders. The independent *t*-tests for the continuous variables show the means on all the variables of the two groups were similar. The Fisher exact results confirm the frequencies of the conditions are not significantly different between the two groups.

The baseline results show this COPD LTOT population are mainly an older female population. The number of people living in rest homes (n=4) was too small for a separate analysis. Ten percent of the population were 60 years or younger. Most people had been on LTOT for over two years with one person being on LTOT for nearly 19 years. The FEV1 results indicate that people had mainly very severe COPD (FEV1 <30% predicted *or* FEV1 <50% predicted plus chronic respiratory failure). There were four people whose last recorded spirometry showed only mild

COPD (FEV1 80%) and no hospital spirometry records were located for eight people. Each of the eight people had a documented physician diagnosis of COPD recorded in clinic letters, oxygen prescriptions and/or discharge summaries. Six of the eight had been on LTOT for one to three years and two people had been on LTOT for 10 years.

Table 5.1: Demographic and clinical characteristics of the responders and non-responders

Characteristic	Values	Returned n = 63 (100%)	Not returned/ declined n = 10 (100%)	Significance
Gender	Male	27(43%)	2(20%)	Fisher's exact p = 0.297
	Female	36(57%)	8(80%)	
Age	Mean(SD)	72(8.7)	72(7.0)	t = 0.016, df = 71, p = 0.987
	Range	54-89	59-79	
FEV1%	Valid	55(87%)	8(80%)	
	Missing	8(13%)	2(20%)	
	Mean (SD)	37(17)	41(16)	t = -0.599, df = 61, p= 0.551
	Range	13-80	29-80	
o2 Rx	16/16+ hours	46(73%)	7(70%)	Fisher's exact p = 0.607
	24 hours	10(16%)	3(30%)	
	PRN	5(8%)		
	Nocturnal	2(3%)		
Months on o2	Mean (SD)	48(47)	43(39)	t = 0.287, df = 71, p = 0.775
	Range	4-216	3-132	
Hospital admission	Yes	37(59%)	6(60%)	Fisher's exact p = 1.000
	No	26(41%)	4(40%)	

Over half of the total population had had an inpatient hospital stay in the previous 12 months. Twenty people (27%) having had one admission and 23 (31%) had between two and five admissions. These admissions had resulted in a total length of stay (LOS) of ≥10 days for 17 people (39%) and a LOS of over 20 days for six people (14%).The results shown in Table 5.1 confirm that 89% (n=56) of prescriptions are for oxygen to be used between 16-24 hours per day.

Responder's additional descriptions

The additional demographic and clinical (relating to COPD management) characteristics collected from the 63 respondents are shown in Table 5.2. Given the mean age (72 years) of the population, the high number of retired people shown in Table 5.2 was not unexpected. Māori only and Māori plus European represent 22% (n=14) of the responders and nearly 10% (n=6) of the responders identified themselves as being of Pacific Island ethnicity. The results indicate that 43% (n=27) of responders had either not attended pulmonary rehabilitation or didn't know whether they had attended. The majority of people who had attended pulmonary rehabilitation had done so 12 or more months ago. Over 70% (n=46) indicated they did not have portable oxygen to use outside the house. Several of this study's

participants put additional comments on their questionnaire, saying they would like portable oxygen. Seven people on LTOT (generally prescribed for 15+ hours) were prescribed either nocturnal or PRN oxygen and six of these people were using their oxygen fewer than 15 hours per day. Additionally, 32% (n=18) of the responders prescribed LTOT for 16-24 hours per day reported using it for fewer than 15 hours per day.

Table 5.2: Demographic and clinical (COPD management) features of responders

Characteristic	Values	Returned n = 63 (100%)
Ethnicity	Māori	11(17.5%)
	European	40(63.5%)
	Pacific	6(9.5%)
	Asian	1(1.6%)
	Other	2(3.2%)
	Māori and European	3(4.8%)
Employment	Retired	52(83%)
	Paid work	2(3%)
	Unemployment	4(6%)
	Other benefit	4(6%)
	Self employed	1(2%)
Lives alone	Yes	18(29%)
	No	44(70%)
	Missing data	1(1%)
o2 usage in hours	<5	4(6%)
	5-9	5(8%)
	10-14	17(27%)
	15-19	17(27%)
	20 or more	20(32%)
Portable o2	Yes	17(27%)
	No	46(73%)
Pulmonary Rehab	Yes	36(57%)
	No	17(27%)
	Don't know	10(16%)

DEPRESSION SCORES

In Figure 5.1 the histogram has the tail to the right showing fewer people had higher depression scores at the upper end of the distribution. The distribution of this variable guided the use of non-parametric statistical tests to compare means across the other variables in relation to the depression scores.

Of the 14 who reported a history of depression all but one (who was currently on treatment for depression) had a PHQ-9 score of 5 or more. In total, nine of the 14 respondents were being treated for depression. One of the responders, who did not report a history of depression, reported they were on current treatment for depression; their PHQ-9 score was zero.
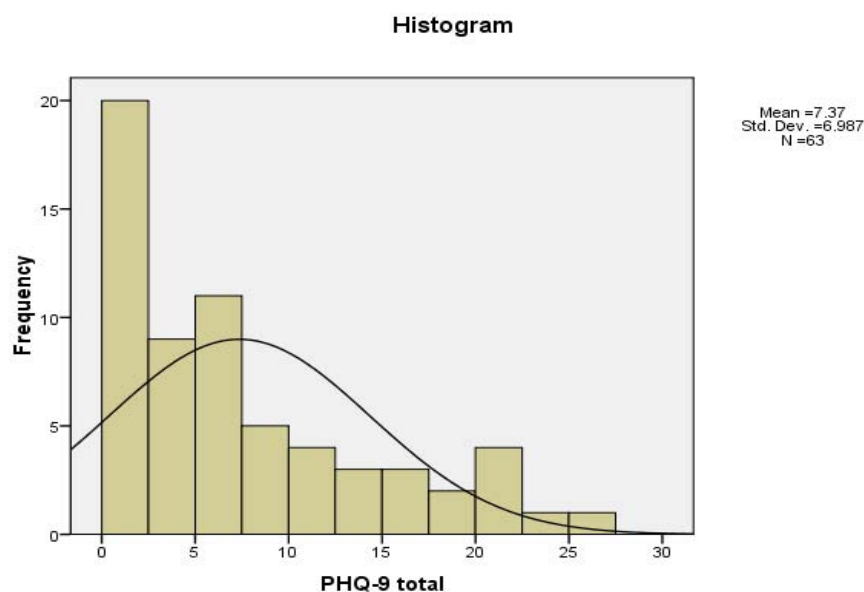
Figure 5.1: Histogram of distribution of the PHQ-9 scores

The results of the depression questions are presented in Table 5.3. The prevalence
of depression was defined as the percentage of depressed patients among the total
number of patients that were surveyed. The overall point prevalence of depression as
measured using the self reported patient health questionnaire-9 (PHQ-9) when a
score was 5 or more was 54% (n=34) (95% CI 41.71 - 65.87). The depression scores
for 29% (n=18) of people indicated moderate to severe depression (score 10-27).
Although over half of the respondents' PHQ-9 scores indicated depression, fewer
than a third reported a history of depression.

Table 5.3: PHQ-9 scores and depression history of the responders

Characteristic	Values	Returned n = 63 (100%)
PHQ 9 total score	Mean (SD) Median Range	7(7) 6 0-27
PHQ-9 scale (95% CI)	None (0-4) Mild (5-9) Moderate (10-14) Moderately severe (15-19) Severe (20-27)	29(46%) CI 34.13 – 58.29 16(25%) CI 15.92 – 37.08 7(11%) CI 5.11 – 20.58 5(8%) CI 3.09 – 16.52 6(10%) CI 4.07 – 18.58
History of depression	Yes No Missing data	14(22%) 48(76%) 1(2%)
Current treatment for depression	Yes No	10(16%) 53(84%)

Table 5.4 shows that two of the six people reporting symptoms of severe depression were not being treated for depression. Nine of the 12 people with moderate to moderately severe depression were not being treated for depression.

Table 5.4: PHQ-9 severity scores and depression treatment

PHQ-9 severity	Depression Rx Yes	Depression Rx No	Total
None	1	28	29
Mild	2	14	16
Moderate	1	6	7
Moderately severe	2	3	5
Severe	4	2	6
Total	10	53	63

Forty (63%) responders consented to their general practitioner (GP) being informed of their PHQ-9 results.

Predictors of depression

Table 5.5 highlights there were no significant correlations between the PHQ-9 total scores and a person's age, FEV1, number of hospital admissions and length of time a person has been on long term oxygen therapy. Spearman's correlations were used as the data was treated as non-parametric.

Table 5.5: Correlations between the PHQ-9 total scores and demographic and clinical characteristics

PHQ-9 total	Spearman's correlation	Sig.(2-tailed)
Age	.036	0.77
FEV1	.139	0.31
Months on oxygen	.151	0.24

There were also no statistically significant differences on the subgroup analyses of the demographic and clinical variables (Table 5.6). Non-parametric statistics were used because of the data distribution of the PHQ-9 scores. However, there was a near significant result for the living alone variable. Those who lived alone had higher PHQ-9 scores indicating the likelihood of more serious depression than those living with others. The box plot shown in Figure 5.2 presents the distribution of the PHQ-9 scores by gender. Female respondents reported more moderate to severe depression scores.

Table 5.6: Demographic and clinical factors that impact on depression

Characteristic	Values	No	Median (IQR)	Mann Whitney *U*
Gender	Male	27	7 (2-10)	$z = -0.237, p = 0.813$
	Female	36	5.5 (2.0-14.5)	
Lives Alone	Yes	18	9.5 (2-19)	$z = -0.364, p = 0.088$
	No	44	4.5 (2-8)	
Portable o2	Yes	17	7 (2.0-14.5)	$z = -0.738, p = 0.460$
	No	46	6 (1.75-10.25)	
Using less o2 than Rx	Yes	40	5.5 (2-10.75)	$z = -0.172, p = 0.864$
	No	23	7 (2-13)	
Completed pulmonary rehab	Yes	36	3.5 (2.0-7.75)	$z = -0.364, p = 0.716$
	No	17	7 (0.5-11.5)	
Hospital admission	Yes	37	4 (1-10)	$z = -1.78, p = 0.750$
	No	26	7 (3.0-12.25)	
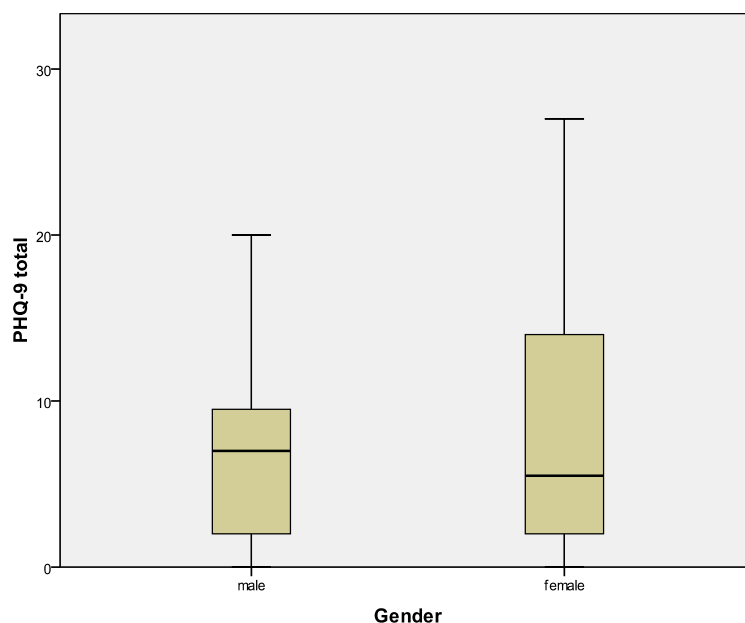
Figure 5.2: Box and whisker plot of mean PHQ-9 total scores by gender*
*Mean (bar), upper and lower quartiles (edges of box), and 95% data coverage (end of whiskers)

SUMMARY

This cross-sectional prevalence study has reported on the incidence of depression amongst a total DHB population of people with COPD on long term oxygen therapy. The clinical, service and research implications of these findings and their relevance to nursing practice are discussed in the next chapter.

CHAPTER 6 – DISCUSSION AND CONCLUSION

The focus of this observational research was to ascertain the prevalence of depression amongst people with chronic obstructive pulmonary disease (COPD) on long term oxygen therapy (LTOT) in a large urban region in New Zealand (NZ). The study's objectives were to 1) describe the characteristics of depressed and not depressed people with COPD on long term oxygen therapy 2) inform the introduction of a validated depression screening tool as standard in practice 3) add to the total body of knowledge about depression in this patient population and provide new information about the prevalence of depression in a NZ COPD LTOT population, and 3) inform future service provision for COPD LTOT patients in the community setting.

Following a comprehensive literature search (Chapter 3) it became evident that there was limited research about the prevalence of depression in LTOT COPD populations. There are a number of studies about depression prevalence in general COPD populations, but there is significant heterogeneity in the published studies design and methodology. In this chapter the design, methods and findings of this point prevalence study will be discussed and compared in relation to the two most recent identified published studies, (Lacasse et al., 2001; Lewis et al., 2007) that examined depression prevalence in COPD LTOT populations. The limitations of this research, future research and practice recommendations that emerged through this study will also be presented

The main findings

A quarter of patients in this study reported mild symptoms and nearly a third had moderate to severe symptoms of depression using the Patient Health Questionnaire-9 (PHQ-9). Although almost one in three people surveyed reported significant depression symptoms, only one in six people reported they were currently being treated for depression (see table 5.4). The study participants were not asked to specify what that treatment was. This is new knowledge regarding the important issue of depression amongst people with COPD on LTOT in New Zealand. It adds weight to the total body of knowledge regarding the high prevalence of depression in COPD LTOT populations.

Demographic and clinical profiles

Overall this study reported demographic and clinical information was similar to Lacasse et al. (2001) and Lewis et al. (2007). The age, gender, diagnosis of COPD using the GOLD (NIH) criteria, whether a person lived alone, length of time on

oxygen, type of oxygen delivery systems (stationery and portable) and whether a person was currently being treated for depression were reported. Both Lacasse et al. and Lewis et al. asked about co-morbidities. Lacasse et al. asked about education and Lewis et al. asked whether the person was housebound and had had any major or upsetting life events e.g. hospital admission or bereavement in the past six months. This study sought hospital admission and length of stay data for the population from hospital records.

Lewis et al. (2007) had also asked about current smoking status, this study did not seek to collect that information given that smoking is contraindicated in the NZ oxygen provision specifications (MOH, 2001a). It was felt that inclusion of this question could limit participation and also those currently smoking might not accurately report this. Lewis et al. study examined the prevalence of anxiety as well as depression and compared LTOT and non-LTOT patients with chronic obstructive pulmonary disease. Lacasse et al. (2001) examined the relationship between depression scores and a validated medical (not chronic respiratory specific) quality of life questionnaire. This study focused additional reporting on ethnicity, the oxygen prescription in hours per day and the actual hours a person used their oxygen for and whether they had attended pulmonary rehabilitation. These additional items captured important information to this study's context about the number of Māori on LTOT, prescription adherence, and hoped to identify any impact on mood pulmonary rehabilitation has.

Data collection

Previous literature reviews (Maurer et al., 2008; van Ede et al., 1999) have highlighted the heterogeneity of studies examining the prevalence of depression in COPD. van Ede et al. recommended that studies needed to include good methodological design, use a validated depression measure for COPD patients and be adequately powered. This study addressed all three recommendations. It was well designed, used an instrument validated for use in New Zealand and the study was adequately powered. In addition because of the high response rate (86%), response bias was minimised. The response rate in this study was significantly higher than the response rates for both Lacasse et al. (2001) and Lewis et al. (2007) which reached just over 60%, suggesting this study had an effective data collection process for a study of this type. Given the high response rate and the fact that this study sampled the total District Health Board (DHB) COPD LTOT population, the responders and non-responders clinical and demographical characteristics collected are highly representative.

This study employed a data collection tool and approach that was widely used, simple, acceptable and relatively quick to complete for those participating. Lacasse et al. (2001) and Lewis et al. (2007) both discussed that ease of completion was a factor in their choice of depression measurement tool. This study utilised the PHQ-9 depression assessment tool. The PHQ-9 can be self-completed and has been validated and recommended for use in NZ, primary care and COPD. As this was the first prevalence study in this population in NZ the use of this measurement tool was appropriate to this study's context. Lacasse et al. used the Geriatric Depression Scale (GDS) in an attempt to improve the estimation of depression in the generally older COPD LTOT population. They concluded that many depression questionnaires include items that may be part of the aging process, such as early morning waking and reduced libido and the inclusion of such items could over estimate the depression prevalence in this population. These items are not included in the PHQ-9. Lewis et al. had used the Hospital Anxiety and Depression Scale (HADS) a tool developed originally for hospital use that measures anxiety also.

The variables collected and the statistical analysis sought to establish the overall prevalence of depression with the secondary aim to inform potential service and practice improvements for the COPD LTOT population. Defining the characteristics of the total population, establishing the prevalence of depression amongst the responders and examining the distribution of their depression scores was done to achieve the primary aim. Examining the differences and correlations when the depression score is the dependant variable and demographic and clinical variables are introduced to see whether a significant change is produced, was completed to add valuable insights for practice.

The findings compared

The overall depression prevalence rates were not dissimilar in this study (with mild cases 25% and moderate to severe depression 29%) compared to Lewis et al. (2007) (with borderline cases 35% and definite cases of depression 26%). Lacasse et al. (2001) found higher rates of depression in their study population (57% significant symptoms and 18% severely depressed). It is difficult to draw any conclusions about the specific numbers as different measurement tools were used. However, this study's results are in line with these previous similar studies highlighting the importance of mood disturbance in this population.

Depression in COPD is important, as well as personal morbidity (Cully et al., 2006) it has been associated with increased utilisation of healthcare resources and early

death (de Voogd, 2009; Gorecka et al., 1997; Gudmundsson et al., 2005; Ramset et al., 2007). Whether LTOT, in addition to COPD alone, contributes to depression is unknown. Lewis et al. (2007) results suggested that patients with severe COPD on LTOT have similar prevalence of symptoms of anxiety and depression (using the Hospital Anxiety and Depression Scale) to those with severe COPD who do not meet the criteria for long term oxygen therapy.

This current study found that 32% of people were using their oxygen for fewer than 15 hours a day, even though the prescription and advice is to use their oxygen for 15 hours or more every day. Depression has been associated with poor treatment adherence (Cully et al.; 2006; DiMatteo et al.; 2000). However, there were no differences in the mean depression scores for those using their using their LTOT for 16-24 hours compared to those who were using it less than 15 hours. Additionally the results did not show any clear relation between depression scores and the length of time a person had been on long term oxygen therapy. Nor were there any differences in mean depression scores for those with portable oxygen. This study's results like Lewis et al. (2007) suggest that LTOT does not have an impact on depression symptoms. The lack of positive impact from LTOT on the PHQ-9 scores could relate to the fact that LTOT is generally prescribed late in the disease continuum where, very often a person is substantially limited functionally and so they may not be able make meaningful physical and emotional gains with the introduction of oxygen.

This study also examined the differences and correlations in depression scores in the widely acknowledge beneficial intervention, pulmonary rehabilitation and factors known to impact negatively (i.e. hospital admissions, living alone) in COPD populations. Interesting, only living alone came close to statistical significance. Lewis et al. (2007) showed statistical significance in depression scores with the addition of socio-demographic variables (i.e. house bound, lives alone). The lack of impact between attendance at pulmonary rehabilitation and the depression scores may be related to most of the study participants having completed the programme more than 12 months before the research. It is generally accepted that the benefits of pulmonary rehabilitation wane over time (American Thoracic Society, 1999). Similar to this study Lacasse et al. (2001) did not find any correlations or difference between the depression scores and any of the demographic and clinical characteristics.

An important finding of this study is that depression is undertreated and perhaps under recognised. This was also shown by Lacasse et al. (2001) and Lewis et al. (2007). It has been suggested that the issue of depression in COPD is complex due

to the "overlap" of the symptoms of depression and COPD (NIH, 2007; APA, 2000). This "overlap" suggests mood disturbance follows the functional decline seen as COPD progresses. Research (Coventry & Hind, 2008; Kunik et al., 2008; NZGG, 2008) indicates that targeted interventions such as cognitive behavioural therapy, pulmonary rehabilitation and medications are effective in addressing depression symptoms in chronic obstructive pulmonary disease. Regarding the "overlap" pulmonary rehabilitation specifically addresses the pulmonary and extra pulmonary effects of chronic obstructive pulmonary disease. Treatment for depression needs to be targeted and a combination approach may be more beneficial for some people.

As discussed in Chapter 2 there are opportunities for improved holistic care provided by community health services (CHS) for COPD patients. It may be earlier recognition of and referral for depression would improve treatment uptake. In practice, factors such as time constraints, patient preferences, the priorities of the nurse involved in the person's care and communication problems may explain some of the limitations in addressing the assessment, treatment and follow-up of depression. It appears that isolation maybe a major interrelated factor for depression in older severe COPD LTOT populations, this is difficult to fully address. Although there are some options for social and interventional outings and increased caregiver support at home, many people still spend large amounts of time alone. The choice to leave one's own environment and go into a rest home setting may not be an acceptable alternative for many people. It is also not known whether COPD LTOT patients are less depressed in residential facilities. As discussed in Chapter 5 the number of study participants living in a rest home (n=4) was too small for separate analysis and people living in hospital level care facilities are not part of the CHS COPD LTOT population (see page 3).

The process regarding patients PHQ-9 results follow-up was followed according to the procedures detailed in the consent form and information sheet (Appendix 2 and 3). The district nurses who work with these patients have reported that generally those with positive depression scores wanted to follow-up with their own general practitioner. At the time of writing this conclusion the researcher is not aware of the outcomes of this follow-up for all the patients. However, three patients are being seen for support more regularly by the community health service (CHS) nurses and four people have agreed to attend a refresher pulmonary rehabilitation programme. Patients that requested the overall study results have been forwarded the thesis abstract.

This study's strengths and limitations

Clear strengths of this current study that contribute to the validity of the results are that it was a total population sample and the characteristics of the population (responders and non-responders) were described. Additionally ethics was well managed, it was sufficiently powered, a validated depression screening tool was used, it had very complete data and a systematic approach to the data analysis were undertaken.

Using a delivered freely available (i.e. on line) self-completed depression tool is open to reporting bias. This was considered and partially addressed by statements in the participant information and consent forms, which aimed to ease concerns a person may have had about reporting depression symptoms. Any bias of this study's design needs to be balanced with the simplicity of administration, low cost and the prevention of interviewer bias.

LTOT has been shown to have physiological benefits and improve neuropsychiatric functioning in COPD patients (Balter et al., 2002; Weidzeicha, 2000; MRC, 1981; NOTT, 1980). This study identified that a significant number of the participants were not adherent to their oxygen prescriptions. A retrospective CHS notes review was not conducted to check the last recorded pulse oximetry result (oxygen saturations) and due to the nature of the study's design a pulse oximetry was not done at the point of data collection. Because of these factors it cannot be guaranteed that all hypoxia was corrected at the time of the PHQ-9 assessment. However, no research to date has provided sufficient evidence about the impacts of short periods of hypoxia for people receiving long term oxygen therapy. People with chronic hypoxia who are not using their oxygen for over 15 hours per day are not likely to benefit in terms of reduced premature mortality (MRC, 1981, NOTT, 1980).

RECOMMENDATIONS FOR RESEARCH AND PRACTICE

The PHQ-9 should be used for future research examining the prevalence of depression amongst people with COPD and other long-term conditions in NZ to determine homogeneity of studies. The study's high response rate and complete data provides evidence that people found the screening tool acceptable and simple to complete.

Portable oxygen is on the agenda for LTOT patients, service providers and researchers. Although this study's results did not show any clear correlations in depression scores for those who have portable oxygen and those that do not, fewer

than 30% of the study participants reported they had access to portable oxygen and several commented they would like to have it. In practice portable oxygen is often requested by patients and families. It can be provided for attending special social functions or appointments but is not given routinely to all LTOT patients.

The National Heart, Lung, and Blood Institute (NHLBI) working group have published a report that outlines recommendations for future research relating to LTOT treatment in COPD. This report states that a randomised double–blinded efficacy trial to test the hypothesis that clinical outcomes are better for those who receive oxygen during activity compared to those who don't is a very high priority (Croxton & Bailey, 2006). Nevertheless, the provision of portable oxygen is becoming more standard as part of the package support for people on LTOT. Current national and international published guidelines (NIH, 2007; Wedzicha & Calvery, 2006; Young, Crockett, & McDonald, 2005) are beginning to reflect and guide this. In light of the study findings the researcher has reviewed the local oxygen policy to include the prerequisites for the supply of portable oxygen. Through consultation with other specialists the DHB has extended the provision of portable oxygen based on a clinical assessment carried out in conjunction with pulmonary rehabilitation. Light weight portable oxygen devices are now available for people who are significantly hypoxic with activity, are active and spend significant amounts of time outside the house for example people that work. This would appear to be appropriate given that this study has identified that 10% of the local population is <60 years old.

The level of depression in this population prior to commencing oxygen is not known. It is also not known whether starting oxygen early in the course of COPD, before permanent physiological changes occur would make a difference in health outcomes. Until such interventions are examined, strategies that improve the recognition and treatment of depression in this population should be the main concern for those caring for people with COPD on long term oxygen therapy. Research using the PHQ-9 screening tool pre and post the introduction of LTOT may be valuable. However, in practice generally people with severe COPD are commenced on LTOT, often following a hospital admission. Pre and post prevalence research would be complex unless COPD patients were routinely screened for depression in a primary care setting. It would potentially require a long time frame and involve intermittently screening a large number of patients with the PHQ-9 and then if and when they are commenced on LTOT (not all people with COPD go onto meet the criteria for LTOT) re screening them.

Community nurses providing home care for people with complex long term conditions are well placed to add the PHQ-9 questionnaire to their tool kit of assessments to guide referral and care planning. This study had a high response rate suggesting very high acceptability of being screened for depression. However, the results also indicated a third of people may not want to complete such a screening tool in practice if the results were going to be discussed with their general practitioner. The PHQ-9 would need a carefully planned introduction into practice to ensure it becomes acceptable to people. The researcher recommends the PHQ-9 should be offered and completed with consent on all COPD LTOT patients three months (to allow time to get used of the oxygen) after referral to the service. This would give a base line result that can be used as a vehicle for discussion with a patient, communication with the general practitioner (GP) and consideration of any other appropriate multidisciplinary interventions, such as pulmonary rehabilitation. Additionally, early recognition and treatment of depression may improve a person's adherence to their long term oxygen therapy prescription. The benefit for patients of routine screening of depression is an area that requires evaluation. It is recommended that the Community Health Service (CHS) complete an evaluation when the PHQ-9 is introduced through a retrospective notes review. Documentation showing referral for GP follow-up, any treatment commenced as a result of screening, comments from conversations with patients, improved adherence to LTOT and repeat PHQ-9 scores indicating no or less depression symptoms could provide evidence about the impact of routine screening.

CONCLUSION

This study provides new evidence regarding the prevalence of depression in NZ COPD LTOT populations. It provides further evidence that depressive symptoms and moderate to severe depression are highly prevalent in patients with COPD on long term oxygen therapy. There is evidence that depression is under treated in this population. As COPD best practice guidelines are updated, providing more specific pathways to guide the screening, treatment and referral of depression in people with COPD would be beneficial to steer best practice.

This study provides verification regarding the usability and acceptability of the PHQ-9 depression questionnaire for people with COPD long term oxygen therapy. This study has informed two main recommendations. Firstly, the PHQ-9 should be used in future research examining the prevalence of depression in people with COPD and other long-term conditions. Secondly, the PHQ-9 screening tool should be included in the tool kit of validated instruments used by community nurses to guide the care of people with COPD on long term oxygen therapy.

APPENDICES

Appendix 1: Ethics approval

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**Health
and
Disability
Ethics
Committees**

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Central Regional Ethics Committee
Ministry of Health
Level 2, 1–3 The Terrace
PO Box 5013
Wellington
Phone: (04) 496 2405
Fax: (04) 496 2191
Email: central_ethicscommittee@moh.govt.nz

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?0 July 2009

Emma Mold
Community Respiratory Clinical nurse Specialist
Capital Coast District Health Board
Wellington Regional Hospital

Dear Emma Mold

**CEN/09/06/041 - The Prevalence of depression Amongst patients with Chronic Obstructive
Pulmonary Disease on Long-term Oxygen Therapy [Re-submission]**

The above study has been given ethical approval by the **Central Regional** Ethics Committee.

Approved Documents:
- Consent Form, Version 3, dated 01/07/2009
- Information Sheet, Version 2, dated 16/06/2009
- Appendix 4: Questionnaire: The rate of depression for people with chronic obstructive pulmonary disease who are on long-term oxygen therapy.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report
The study is approved until **1 December 2009**. A final report is required at the end of the study. The report form is available on http://www.ethicscommittees.health.govt.nz and should be forwarded along with a summary of the results. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Amendments
It is also a condition of approval that the Committee is advised if the study does not commence, or is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

S Scott

Sonia Scott
Central Regional Ethics Committee Administrator

Email: sonia_scott@moh.govt.nz

Administered by the Ministry of Health   Approved by the Health Research Council   http://www.ethicscommittees.health.govt.nz

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI
VICTORIA
UNIVERSITY OF WELLINGTON

Consent Form
What is the prevalence of depression for people with Chronic Obstructive Pulmonary Disease (COPD) who are on Long Term Oxygen Therapy?

English	I wish to have an interpreter.	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhakaMāori/kaiwhaka pakeha korero.	Ae	Kao
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai
Samoan	Ou te mana'o ia i ai se fa'amatala upu.	Ioe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai

I have read and I understand the information sheet dated *16.06.09* for volunteers taking part in the study designed to find out the rate of depression for people with Chronic Obstructive Pulmonary Disease (COPD) who are on Long Term Oxygen Therapy.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my continuing health care.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part.
I agree to my depression questionnaire results being sent to my GP.
       YES/NO
I would like a Nurse to discuss the overall outcomes of the study with me.
       YES/NO
I _____ (full name) hereby consent to take part in this study.
  Signature _____   Date_____

 Project explained by _____
 Signature _____   Date _____

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI

VICTORIA
UNIVERSITY OF WELLINGTON

Information Sheet
What is the prevalence of depression for people with Chronic Obstructive Pulmonary Disease (COPD) who are on Long Term Oxygen Therapy?

Introduction

You are invited to take part in this study looking at the rate of depression for people with COPD who are on Long Term Oxygen Therapy being conducted by Emma Mold. This study will be written up as a thesis as part of a masters in nursing and is supported by Dr Katherine Nelson Senior Lecturer and Alan Shaw Lecturer from Victoria University of Wellington.

There is some evidence that depression is not sufficiently recognised in people with long-term breathing problems. This study aims to determine the rate and understand the extent of depression, to better inform health services and the type of support provided for people on long term oxygen.

Ethics approval has been granted for this study by the Central Region Ethics Committee of New Zealand.

Who and what is involved?

- All people with COPD on long term oxygen throughout the Wellington region will be invited to participate.

- If you need an interpreter one can be provided.

- You are asked to fill in two short questionnaires for this study. One is a general individual information questionnaire and the second is a questionnaire (PHQ-9) to assess for depression. The PHQ-9 is a screening questionnaire only and positive results would not necessarily mean you have depression.

- The questionnaires will take 10-15 minutes in total for you to complete. You do not have to answer all the questions.

- Once you have completed your questionnaires you can post them back in the stamped envelope provided or arrange with your nurse to have them collected.

- **No** material which could personally identify you will be used in any reports on this study.

Page 1 of 2   **Information sheet for prevalence study**
Version 2   Approved 16.06.09

- Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part you will receive the usual care. If you do agree to take part you are free to withdraw from the study at any time, without having to give a reason and this will in no way affect your continuing health care.

What happens to the results?

- Your own consent form and questionnaires will be filed in your hospital record.

- With your consent, the results of your depression questionnaire will be forwarded to your GP.

- The nurse will follow-up with you about the depression questionnaire results if your answers indicate you may have depression.

- All computerised research information will be stored in a password protected computer file for 5 years.

- The overall results of the research will be written as a thesis lodged at Victoria University library, presented at conferences and written up in a journal. Please note there will be a delay of up to 12 months from information collection and the final written thesis report.

Study and supervisor contact details:

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Appendix 4: General Practitioner letter

Capital & Coast
District Health Board
ŪPOKO KI TE URU HAUORA

OUTPATIENT LETTER
Community Health Service

Date

RE: (inset name and NHI)

Dear Dr

(Inset patient name) was seen at home on the (insert date) and as part of a study aimed to determine the prevalence of depression in people with COPD on Long Term Oxygen Therapy. The Patient Health Questionnaire (PHQ-9) depression assessment questionnaire was completed. The prevalence study is part of Emma Mold's research for her Master of Nursing (Clinical) which is being undertaken under the supervision of Dr Katherine Nelson, Graduate School of Nursing, Midwifery and Health, Victoria University of Wellington.

Please find attached (insert patient name) results for your records.

The patient has been advised to see you for further assessment if their results indicate depression.

Yours Sincerely

Emma Mold
Community Respiratory Nurse Clinician
Community Health Service

Appendix 5: Whanau care letter

08 June 2009

Emma Mold
Respiratory Clinical Nurse Specialist
Community Health Services
Capital & Coast District Health Board
Telephone (04) 918 6384 027 479 3935

Tena koe Emma

Re: What is the prevalence of depression for people with chronic obstructive pulmonary disease on long term oxygen

Further to our conversation about the above research proposal. You have requested that Whanau Care Services support the Māori participants who may be recruited for this study including appropriate support for themselves and their whanau.

We are able to support this request if you require brochures for Whanau Care Services please do not hesitate to contact me.

Please feel free to contact me should you have any more enquiries.

Nāku noa, nā

Helena Keyes
Nurse Coordinator
Whanau Care Services
CCDHB
04 3855956
Helena.keyes@ccdhb.org.nz

Appendix 6: Developed patient questionnaire

<div style="border: 1px solid black;">

Thank you for agreeing to take part in this research
There are 2 questionnaires attached for you to complete

</div>

1. Name_____

2. Age_____

3. Gender: Male ☐   Female ☐

4. Please indicate which ethnic group(s) you identify with. *Tick as many as are applicable*
[   ] NZ European
[   ] Māori
[   ] Pacific Island
[   ] Asian
[   ] Other (please describe) _____

5. What is your employment status (e.g. retired, unemployed, paid work (part time / fulltime)?
_____

6. Do you live alone?   **Yes** ☐ **No** ☐

7. How many hours each day do you use your home oxygen? *Tick one*
[   ] Less than 5 hours a day
[   ] 5 - 9 hours
[   ] 10 - 14 hours
[   ] 15 - 19 hours
[   ] 20 or more hours

Please comment on your home oxygen use if you wish

_____

_____

8. Do you have a small portable oxygen cylinder to use outside the
house (e.g. for shopping, regular social events or work)?   **Yes** ☐ **No** ☐

9. Have you completed the 'Pulmonary Rehabilitation Programme'
run by the hospital?   **Yes** ☐ **No** ☐ **Don't know** ☐

If YES, how long ago did you do the programme? _____

10. Have you ever been told by a health professional you have depression? **Yes** ☐ **No** ☐

11. Are you currently being treated for depression?   **Yes** ☐   **No** ☐

Appendix 7: The nine questions of the PHQ-9

Over the last 2 weeks, how often have you been bothered by any of the following problems?

(not at all = 0, several days = 1, more than half the days = 2, nearly every day = 3)

1. Little interest or pleasure in doing things?

2. Feeling down, depressed, or hopeless?

3. Trouble falling or staying asleep, or sleeping too much?

4. Feeling tired or having little energy?

5. Poor appetite or overeating?

6. Feeling bad about yourself - or that you are a failure or have let yourself or your family down?

7. Trouble concentrating on things, such as reading the newspaper or watching television?

8. Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?

9. Thoughts that you would be better off dead, or of hurting yourself in some way?

   Total score = number/27

   Depression Severity: 0-4 none, 5-9 mild, 10-14 moderate, 15-19 moderately severe, 20-27 severe.

Appendix 8: Coding sheet

Prevalence of depression amongst people with COPD on LTOT

Q. No	Variable	Variable Values	Variable type
	No	As per questionnaire	Nominal
	Surveyed	1. Yes 2. No	Nominal
A	Age	In years	Scale
B	Gender	1. Male 2. Female	Nominal
C	Ethnicity	1. Māori ONLY 2. European ONLY 3. Pacific ONLY 4. Asian ONLY 5. Other ONLY 6. Māori AND European 7. Māori AND Pacific	Nominal
D	Employment	1. Retired 2. Paid work 3. Unemployed 4. Other benefit 5. Self employed	Nominal
E	Lives alone	1. Yes 2. No	Nominal
F	FEV1	FEV1 as a percentage	Scale
G	O2 months on	In months	Scale
H	O2 Rx	1. 16 / 16+ hours 2. 24 hours 3. PRN 4. Nocturnal	Nominal
I	O2 Usage	1. < 5 hours 2. 5-9 3. 10-14 4. 15-19 5. 20 or more	Ordinal
J	Portable	1. Yes 2. No	Nominal
K	Prehab	1. Yes 2. No 3. Don't know	Nominal
L	Prehab when	In months	Scale
M	Depever	1. Yes 2. No	Nominal
N	DepRx	1. Yes 2. No	Nominal
O	PHQ-9	Total score (0-27)	Scale
P	PHQ-9scale	1. None (0-4) 2. Mild (5-9) 3. Moderate (10-14) 4. Moderately severe (15-19) 5. Severe (20-27)	Ordinal
	Admissions	Number of admissions	Scale
	LOS	Total inpatient days	Scale
		88. Missing data 99. n/a data	

REFERENCES

Agusti, A., & Soriano, J. B. (2008). COPD as a systemic disease. *COPD, 2*(2), 133-138.

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders, text revision* (4th ed). Washington, DC: American Psychiatric Association.

American Thoracic Society. (1999). Pulmonary rehabilitation. *American Journal of Respiratory and Critical Care Medicine, 159*(5 [Pt 1]), 1666-1682.

Balter, M. S., Daniak, N., Chapman, K. R., Sorba, S. A., & Rebuck, A. S. (1992). Erythropietin response to acute hypoxemia in patients with chronic pulmonary disease. *Chest, 102*, 482-485.

Barr, R., Celi, D., Mannino, T., Petty, S., Rennard, F., Sciurba, J., et al. (2009). Co morbidities, patient knowledge, and disease management in a national sample of patients with COPD. *The American Journal of Medicine, 122*(4), 348-355.

Beekman, A.T., Copeland, J.R., & Prince, M.J. (1999). Review of community prevalence of depression in later life. *The British Journal of Psychiatry, 174*, 307-311.

Borak, J. S. P., Piasecki, Z., & Zielinski, L. (1991). Psychological status of COPD patients on long term oxygen therapy. *European Respiratory Journal, 4*, 52 - 62.

Brashers, V. L. (2002). Structure and Function of the Pulmonary System and Alterations of Pulmonary Function. In K. L. McCance & S. E. Heuther. (Eds.), *Pathophysiology the biological basis for disease in adults & children* (4th ed., pp. 1082-1135). St Louis: Mosby Inc.

Celli, B. R., MacNee, W., Agusti, A., Anzueto, A., Berg, B., Buist, A. S., et al. (2004). Standards for the diagnosis and treatment of patients with COPD: A summary of the ATS/ERS position paper. *European Respiratory Journal, 23*, 932-946.

Cooper, C. B., & Dransfield, M. (2008). Primary care of the patient with chronic obstructive pulmonary disease-part 4: Understanding the clinical manifestations of a progressive disease. *The American Journal of Medicine, 121*(supplement 7), S33-45.

Coventry, P. A., & Hind, D. (2007). Comprehensive pulmonary rehabilitation for anxiety and depression in adults with chronic obstructive pulmonary disease: Systematic review and meta-analysis. *Journal of Psychosomatic Research 63*, 551-565.

Croxton, R. L., & Bailey, W. C. (2006). Long-term oxygen treatment in chronic obstructive pulmonary disease: Recommendations for future research. An NHLBI Workshop Report. *American Journal of Respiratory and Critical Care Medicine, 174*, 373-378.

Crumbie, A. (2000). The patient as partner in care. In M. Walsh. A, Crumbie & S. Reveley (Eds). *Nurse practitioners clinical skills and professional issues (*pp 239-248). Oxford: Reed Elsevier Ltd.

Cully, J. A., Graham, D. P., Stanley, M. A., Ferguson, C. J., Sharafkhaneh, A., Souchek, J., et al. (2006). Quality of life in patients with chronic obstructive pulmonary disease and comorbid anxiety or depression. *Psychosomatics, 47,* 312-319.

Department of Health. (2009). Transforming community services. *Quality framework: guidance for community services.* London, United Kingdom: Author.

de Voogd, J. N., Wempe, J. B., Koëter, G. H., Postema, K., van Sonderen, E., Ranchor, A. V., et al. (2009). Depressive symptoms as predictors of mortality in patients with COPD. *Chest, 135*(3), 619-625.

DiMatteo, M. R., Lepper, H. S., & Croghan, T. W. (2000). Depression is a risk factor for noncompliance with medical treatment: Meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine, 160,* 2101-2107.

Di Marco, F., Verga, M., Reggenete, M., Casanova, M. F., Santus, P., Blasi, L., et al. (2006). Anxiety and depression in COPD patients: The roles of gender and disease severity. *Respiratory Medicine, 100*(10), 1767-1774.

Doll, R., & Hill, A. B. (1954). The mortality of doctors in relation to their smoking habits: a preliminary study. *British Medical Journal,* 1451–1455. DOI:10.1136/bmj.328.7455.1529.

Dum, M., Pickren, J., Sobell, L. C., & Sobell, M. B. (2007). Comparing the BDI-11 and the PHQ-9 with outpatient substance abusers. *Addictive Behaviors, 33,* 381-387.

Fan, V. S., Ramsey, S. D., Giardino, N. D., Make, B. J., Emery, C. F., Diaz, F. T., et al. (2007). Sex, depression, and risk of hospitalization and mortality in chronic obstructive pulmonary disease. *Archives of Internal Medicine, 167*(21), 2345-2353.

Funk, G., Kirchheiner, K., Burghuber, O. C., & Hartl, S. (2009). BODE index versus GOLD classification for explaining anxious and depressive symptoms in patients with COPD: A cross-sectional study. *Respiratory Research, 10*(1). DOI: 10.1186/1465-9921-10-1.

George, J., Kong, D. C., Thoman, R., & Stewart, K. (2005). Factors associated with medication non adherence in patients with COPD. *Chest, 128,* 3198-3204.

Gorecka, D., Gorselak, K., Silwinski, P., Tobiasz, M., & Sielinski, J. (1997). Effects of long term oxygen therapy on survival in patients with chronic obstructive pulmonary disease with moderate hypoxaemia. *Thorax, 52,* 674-679.

Grothe, K. B., Dutton, G. R., Jones, G.N., Bodenlos, J., Ancona, M., & Brantley, P. J. (2005). Validation of the Beck Depression Inventory-II in a low-income African American sample of medical outpatients. *Psychological Assessment, 17*(1), 110-114.

Gudmundsson, G., Gislason, T., Janson, D., Lindberg, E., Hallin, R., Ulrik, C. S., et al. (2005). Risk factors for rehospitalization in COPD: Role of health status, anxiety and depression. *European Respiratory Journal, 26,* 414-419.

Hagen, B. (2007). Measuring melancholy: A critique of the Beck Depression Inventory and its use in mental health nursing. *International Journal of Mental Health Nursing, 16*, 108-115.

Hill, K., Geist, R., Goldstein, R. S., & Lacasse, Y. (2008). Anxiety and depression in end-stage COPD. *European Respiratory Journal, 31*, 667-677.

Jones, P.W., Baveystock, C.M., & Littlejohns, P. (1989). Relationships between general health measured with the sickness impact profile and respiratory symptoms, physiological measures, and mood in patients with chronic airflow limitation. *American Review of Respiratory Disorders, 140*, 1538-1543.

Kim, H. F., Kunik, M. E., Molinari, V. A., Hillman, S. L., Lalani, S., Orengo, C. A., et al. (2000). Functional Impairment in COPD patients: The impact of anxiety and depression. *Psychosomatics 41*, 465-471.

Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: Validity of a brief depression severity measure. *Journal of General Internal Medicine, 16*(9), 606-613.

Kunik, M. E., Roundy, K., Veazey, C., Souchek, J., Richardson, P., Wray, N. P., et al. (2005). Surprisingly high prevalence of anxiety and depression in chronic breathing disorders. *Chest, 127*, 1205 - 1211.

Kunik, M. E., Veazey, C., Cully, J. A., Souchek, J., Graham, D. P., Hopko, D., et al. (2008). COPD education and cognitive behavioral therapy group treatment for clinically significant symptoms of depression and anxiety in COPD patients: A randomized controlled trial. *Psychological Medicine, 38*, 385-396.

Lacasse, Y., Goldstein, R., Lasserson, T.J., Martin, S. Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews* 2006, Issue 4. Art. No.: CD003793. DOI: 10.1002/14651858.CD003793.pub2.

Lacasse, Y., Rousseau, L., & Maltais, F. (2001). Prevalence of depressive symptoms and depression in patients with severe oxygen-dependent chronic obstructive pulmonary disease. *Journal of Cardiopulmonary Rehabilitation, 21*(2), 80 -86.

Lamer, F., Jonkers, C. M., Bosma, H., Penninx, W. J., Knottnerus, J. A., & van Eijk, J. T. (2008). Summed score of the Patient Health Questionaire-9 was a reliable and valid method for depression screening in chronically ill elderly patients. *Journal of Clinical Epidemiology, 61*, 679-687.

Lewis, K. E., Annandale, J. A., Sykes, R. N., Hurlin, C., Owen, C., & Harrison, K. (2007). Prevalence of anxiety and depression in patients with severe COPD: Similar high levels with and without LTOT, *Journal of Chronic Obstructive Pulmonary Disease, 4*(4), 305-312.

Lu, C.Y. (2009). Observational studies: A review of study designs, challenges and strategies to reduce confounding. *International Journal of Clinical Practice, 63*(5) 691-697.

Light, R.W., Merrill, E.J., Despars, J.A., Gordon, G.H., & Mutalipassi, L.R. (1985). Prevalence of depression and anxiety in patients with COPD. Relationship to functional capacity, *Chest, 87*, 35-38.

Loney, P.L., Chalmers, L.W., Bennett, K.J., Roberts, J.G., & Stafford, P.W. (2000). Critical appraisal of the health research literature: Prevalence or incidence of a health problem. *Chronic Disease in Canada.* 19(4), Retrieved September 22, 2008, from http://www.phac-aspc.gc.ca/publicat/cdic-mcc/19-4/e_e.html.

Maguire, P., & Pitceathly, C. (2002). Key communication skills and how to acquire them*. British Medical Journal*, *325*, 697-700.

Mann, C. J. (2003). Observational research methods. Research design II: Cohort, cross sectional, and case-control studies. *Emergency Medical Journal, 20*, 54-60.

Maurer, J., Rebbapragada, V., Borson, S., Goldstein, R., Kunik, M. E., Yohannes, A. M., et al. (2008). Anxiety and depression in COPD: Current understanding, unanswered questions, and research needs. *Chest, 134*(4), 43S-56S.

McKenzie, D. K., Abramson, M., Crockett, A.J., Glasgow, N., Jenkins, S., McDonald, C., et al. (2007) The COPD-X Plan: Australian and New Zealand guidelines for the management of chronic obstructive pulmonary disease.

Medical Research Council Working Party. (1981). Long term domiciliary oxygen therapy in chronic hypoxic cor pulmonale complicating chronic bronchitis and emphysema. *Lancet, 1*, 681-686.

Miller, L. (2002). Effective communication with older people. *Nursing Standard, 17*, (9), 45-50.

Ministry of Health. (2001a). *National service specifications: Home oxygen therapy service.* Wellington, New Zealand: Author.

Ministry of Health*.* (2001b). *National service specification for specialist community nursing services.* Wellington, New Zealand: Author.

Mold, E.J., & Boland, A. (2009) Community health service report: Prepared for the C&C DHB community service steering group. Unpublished: C&C DHB.

Murray, C., & Lopez, A. D. (1997). Global mortality, disability and the contribution of risk factors: global burden of disease study. *Lancet*, *349*, 1436-1442.

National Health Committee. (2007). *Meeting the needs of people with chronic conditions: Häpai te whänau mo ake ake tonu.* Wellington, New Zealand: National Advisory Committee on Health and Disability.

National Institutes of Health. (2007). Global initiative of chronic obstructive lung disease. Global strategy for the diagnosis, management and prevention of chronic obstructive pulmonary disease: Executive summary. Retrieved March 28, 2008, from http://www.goldcopd.com/

New Zealand Guideline Group. (2008). *Identification of common mental disorders and management of depression in primary care. Evidence- based best practice guideline.* Wellington: Author.

Ng, T., Niti, M., Fones, C., Yap, D. B., & Tan, W. (2008). Co-Morbid association of depression and COPD: A population based study. *Respiratory Medicine,* 1-7.

National Institutes for Clinical Excellence (2004).*Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care.* London, United Kingdom: Author.

Nici, L., Donner, C., Wouters, E. F. M., Zuwallack, R., Ambrosino, N., Bourbeau, J., et al. (2006). American Thoracic Society/European Respiratory Society statement on pulmonary rehabilitation. *American Journal of Respiratory and Critical Care Medicine, 173*, 1390-1413.

Nocturnal Oxygen Therapy Trial Group (1980). Continuous or nocturnal oxygen therapy in hypoxemic chronic obstructive lung disease: A clinical trial. *Annals of Internal Medicine, 93*, 391-398.

O'Donnell, D. E., Revill, S.M., & Webb, K. A. (2001). Dynamic hyperinflation and exercise intolerance in chronic obstructive pulmonary disease. *American Journal of Critical Care Medicine*, *164*(5), 770-777.

Peat, J., & Barton, B. (2005). *Medical statistics: A guide to data analysis and critical appraisal* (2nd ed). Cornwall: Blackwell Publishing Ltd.

Restrick, L. J., Paul, E. A., Braid, G. M., Cullinan, P., Moore-Gillon, P., & Wedzicha, J. A. (1993). Assessment and follow up of patients prescribed long term oxygen treatment. *Thorax, 48*, 708-713.

Roberts, L. & Bucksey, S. (2007). Communicating with patients: What happens in practice? *Physical Therapy, 5*(87), 586-594.

Scott, B. P., & Williams, J. V. A. (2007). Chronic obstructive lung disease and prevalence of mood, anxiety and substance-use disorders in large population sample. *Psychosomatics, 48*(6), 496-501.

Seidel, H. M., Ball, J. W., Dains, J. E., Benedict, W.G. (2006). The history and interviewing process. (6th ed).*In Mosby's guide to physical examination.* (pp2-37). St Louis: Mosby Elsevier.

Sharp, L. K., & Lipsky, M. S. (2002). Screening for depression across the lifespan: A review of measures for use in primary care settings. *American Family Physician, 66*(6), 1001-1008.

Simpson, M., Buckman, R., Stewart, M., Maquire, P., Lipkin, M., Novack, D., et al. (1991). Doctor-patient communication: The Toronto consensus statement. *British Medical Journal, 303,* 1385-1387.

Solano, J. P., Gomes, B., & Higginson, I. J. (2006). A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease [Electronic version]. *Journal of Pain and Symptom Management, 31*(1), 58 - 69.

Town, G. I., Taylor, R., Garrett, J., & Patterson, J. (2003). *The burden of COPD in New Zealand*. Wellington, New Zealand: Authors.

United States Preventive Services Task Force. (2002). Clinical guidelines: Screening for depression: recommendations and rationale. *Annals of Internal Medicine, 136*, 760 -764.

van den Bemt, L., Schermer, T., Smeele, I., Bischoff, E., Jacobs, A., Grol, R., et al. (2008). Monitoring of patients with COPD: A review of current guidelines' recommendations [Electronic version]. *Respiratory Medicine 102*(5), 633-641.

van Ede, I., Yzermans, C. J., & Brouwer, H. J. (1999). Prevalence of depression in patients with chronic obstructive pulmonary disease: A systematic review *Thorax, 54*, 688-692.

van Manen, J. G., Bindels, P. J. E., Dekker, F. W., IJzermans, C. J., van der Zee, J. S., & Schadé, E. (2002). Risk of depression in patients with chronic obstructive pulmonary disease and its determinants. *Thorax, 57*(5), 412-416.

von Elm, E., Altman, D.G., Egger, M., Pocock, S.J., Gøtzsche, P.C., Vandenbroucke, J.P. (2007). STROBE Initiative. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: Guidelines for reporting observational studies. *Journal of Clinical Epidemiology*, *61*, 344-349. DOI: 10.1016/j.jclinepi.2007.11.008.

Wagena, E. J., Arrindell, W. A., Wouters, E. F. M., & van Schayck, C. P. (2005). Are patients with COPD psychologically distressed. *European Respiratory Journal, 26*, 242-248.

Wedzicha, J.A. (2000). Effects of long term oxygen therapy on neuropsychiatric function and quality of life. *Respiratory Care*, *45*(1), 119-1124.

Wedzicha, J. A., & Calverley, P. M. A. (2006). All change for home oxygen services in England and Wales. *Thorax, 61*(1), 7-9.

Weitzenblum, E., Oswald, M., Apprill, M., Ratomaharo, J., & Kessler, R. (1991). Evolution of physiological variables in patients with chronic obstructive pulmonary disease before and during long-term oxygen therapy. *Respiration, 58*(3-4), 126-131.

Wilt T.J., Niewoehner, D. K. C., Kane, R.L., Linabery, A., Tacklind, J., MacDonald, R., et al. (2005) Use of spirometry for case finding, diagnosis, and management of chronic obstructive pulmonary disease (COPD*). National Library of Medicine.* Retrieved September 26, 2008, from http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat1b.chapter.5.

Xu, W., Collet, J., Shapiro, S., Lin, Y., Yang, T., Platt, R. W., et al. (2006). Independent effect of depression and anxiety on chronic obstructive pulmonary disease exacerbations and hospitalizations. *American Journal of Respiratory and Critical Care Medicine, 178*, 913-920.

Yeh, M., Chen, H., Liao, Y., & Liao, W. (2004). Testing the functional status model in patients with chronic obstructive pulmonary disease. *Journal of Advanced Nursing, 48*(4), 342-350.

Yohannes, A. M., Baldwin, R. C., & Connolly, M. J. (2002). Depression and anxiety in elderly outpatients with chronic obstructive pulmonary disease: Prevalence, and validation of the BASDEC screening questionnaire. *International Journal of Geriatric Psychiatry, 15*(12), 1090-1096.

Young, I.H., Crockett, A.J., & McDonald, C.F., (2005). Adult domiciliary oxygen therapy: Position statement of the Thoracic Society of Australia and New Zealand. *Medical Journal of Australia, 18*, 621-626.