COPD Dyspnea Palliation Project: Dyspnea Palliation in End-Stage COPD Patients

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By

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Abstract

Chronic Pulmonary Obstructive Disease (COPD) is a chronic and incurable disease that affects over 12 million Americans. The number of people with COPD is rising, and it is the third leading cause of death in the United States. Management and palliation of COPD symptoms has become a public health issue. The capstone project, the COPD Palliation Project, was a pilot study that combined nursing case management and patient education to provide optimal patient dyspnea palliation and self-efficacy of dyspnea management to end-stage COPD hospice patients. For the intervention, end-stage COPD patients were taught to use a dyspnea algorithm to palliate increasing levels of dyspnea, with weekly follow up for four weeks. Patient dyspnea and efficacy were the outcome measures monitored pre and post-intervention. The study findings showed that there was improvement in the percent of patients who scored in less than “2” in the modified Borg scale from 55% to 75% after the intervention. However, there was no improvement in the percent outcome of patients’ efficacy. Improvement in dyspnea scores may be attributed to use of the dyspnea protocol and follow up case management and education. The fact that patient efficacy scores did not improve can be largely attributed to the patients’ terminally ill, end-stage hospice status. Major limitations of the project were: lack of study population viability, limited time to implement the study, staff investment and patient discomfort in using morphine. Further research in combining dyspnea protocols with case management techniques in COPD dyspnea palliation is warranted.

Keywords: COPD, self-management, disease management, palliative care, dyspnea protocol
## TABLE OF CONTENTS

Abstract………………………………………………………………………………..2

Table of Contents……………………………………………………………………..3

Utilizing the COPD Dyspnea Palliation Project……………………………………5
  Statement of Problem……………………………………………………………..5
  Evidence of Problem……………………………………………………………...6
  Review of Literature……………………………………………………………..8
  Conceptual Framework………………………………………………………….12

Project Description…………………………………………………………………13
  Purpose………………………………………………………………………….13

Methods……………………………………………………………………………14
  Study Design……………………………………………………………………14
  Project Setting…………………………………………………………………16
  Participants and Sample Size……………………………………………….18
  Plan and Protocol……………………………………………………………..19
  Agency Support and Materials………………………………………………22

Results………………………………………………………………………………..23
  Data Analysis……………………………………………………………………23
  Dyspnea Self-Management………………………………………………….23
  Impact on Patient Efficacy………………………………………………….24

Discussion………………………………………………………………………….24
  Patient Morphine Usage for Dyspnea……………………………………….25
  Potential Risks………………………………………………………………….26
Limitations..................................................................................................27
Conclusion.................................................................................................29
References ...............................................................................................30
Appendices ..............................................................................................35

Appendix A .............................................................................................35
Appendix B .............................................................................................36
Appendix C .............................................................................................37
Appendix D .............................................................................................38
Appendix E .............................................................................................40
Appendix F .............................................................................................41
Appendix G .............................................................................................42
Appendix H .............................................................................................43
Appendix I .............................................................................................44
Appendix J .............................................................................................45
Appendix K .............................................................................................46
Utilization of the COPD Palliation Project

Statement of Problem

Chronic Obstructive Pulmonary Disease (COPD) is a chronic, incurable disease whose prevalence is increasing globally. The Center for Disease Control (CDC) reports that COPD is the third leading cause of death in the United States (CDC, 2011). Globally, COPD is predicted to be the third leading cause of death by the year 2030 (WHO, 2008). COPD is directly related to smoking, which is a major factor of the increasing rates of COPD.

Patients with COPD progressively deteriorate, with the main symptom being increasing, intractable dyspnea. Treatment is essentially palliative in nature, as COPD cannot be cured. Due to the high prevalence of dyspnea in advanced COPD, it is the main focus of palliative care in these patients. Traditional healthcare approaches and protocols to treat this dyspnea have focused on the pathophysiology of disease and treating bronchoconstriction and reducing hyperinflation and inflammation (Rocker et al., 2009). The standard medical treatments for COPD are: bronchodilator use, supplemental oxygen, pulmonary rehabilitation and other non-medical interventions, such as the use of fans (Rocker et al., 2007). However, this approach is very limited in end-stage COPD, which requires more aggressive management to palliate discomfort associated with dyspnea. Opioids and anxiolytics are crucial components of the end-stage COPD symptom management plan (Rocker et al., 2009). The addition of opioids and anxiolytics to the COPD palliative care regimen has been shown to greatly reduce dyspnea in end-stage COPD patients (Abernathy et al., 2003; Rocker et al., 2007).

Research has shown that nursing case management is a vehicle by which advanced COPD can be managed. The missing piece is a protocol for the clinician to follow in cases of increasing breathlessness. Use of a dyspnea ladder will provide this piece. The dyspnea ladder
is a protocol that combines both traditional methods, as well as use of opioids and anxiolytics, to be followed with increasing dyspnea (Rocker et al., 2007) (See Appendix A). With the dyspnea ladder incorporated into the nurse case management role, a far more viable solution for dyspnea management becomes apparent. The purpose of this capstone project was to measure the effectiveness of this solution for end-stage COPD hospice patients, in terms of both patient comfort and self-efficacy. This data will help to establish evidence-based practice nursing guidelines for end-stage COPD patients.

Evidence of Problem

COPD is a chronic, incurable and progressive disease. It is caused by chronic bronchitis or emphysema and is directly related to smoking and persistent exposure to secondhand smoke (Sat, S., 2012). According to the CDC, over 12 million Americans have been diagnosed with COPD, but another 12 million are most likely undiagnosed or underdiagnosed (CDC, 2011). In the United States, COPD is the third leading cause of death, with 120,000 Americans dying of advanced COPD annually (CDC, 2011). Particularly concerning are the multiple symptoms and poor quality of life in advanced COPD patients (Roberts, Seiger, & Stone, 2008). The palliative care approach required to maintain these patients and control COPD related symptoms is not as readily accessible to these patients as to cancer patients. Their disease prognosis is uncertain and the palliative care criteria is relatively new and unknown to many physicians (Lanken et al., 2007). These patients are also less able to access appropriate palliative care than patients with lung cancer (Gore, Brophy & Greenstone, 2000).

For end-stage COPD patients, the symptom of dyspnea is the universal source of discomfort and anxiety (Rocker et al., 2007). Due to the high prevalence of dyspnea in advanced COPD, it is the main focus of palliative care in these patients. Ironically, dyspnea is also the
symptom that is palliated the least well in end-stage COPD patients (Elkington et al., 2005). This is because traditional medical approaches, such as bronchodilators and steroids, are not effective in relieving end-stage dyspnea and subjective experiences of breathlessness (Elkington et al, 2005). In a 2009 consensus statement by the National Cancer Research Institute, the members of the research panel stated that the management of breathlessness in end-stage and terminal disease is inadequate and that there are relatively few research studies on dyspnea and no universal management guidelines for it (Dorman et al., 2009). Given these facts, it is clear that palliation of COPD symptoms is a public health issue. It is a health challenge because of the rising number of end-stage COPD patients without proper dyspnea palliation; it is a health disparity because palliation that is available to a more concretely diagnosed disease, such as lung cancer, is not fully available to end-stage COPD patients.

The capstone project, the COPD Dyspnea Palliation Project, was a pilot study that focused on palliation of end-stage COPD patient dyspnea and increasing efficacy for end-stage COPD patients within a home hospice setting through nurse led case management. Bourbeau et al. (2003) stated that to better address symptom management and patient efficacy in COPD palliation, nurse case management should be incorporated into palliative care and hospice programs. The COPD Dyspnea Palliation Project combined case management and a dyspnea protocol to achieve better dyspnea palliation and increased patient efficacy.

In the project, a COPD nurse case manager utilized a protocol based on a dyspnea ladder (Rocker et al., 2007), which provided a series of steps for the patient to palliate increasing levels of dyspnea. The nurse case manager then taught these patients to use the protocol to achieve increased palliation of dyspnea and efficacy. A dyspnea survey using a modified Borg Scale (See Appendix E) was used to assess levels of dyspnea. A patient breathlessness survey, using
the MRC Dyspnea Scale was used to measure levels of patient activity-related efficacy (Stenton, 2008) (See Appendix B). Percentage outcomes of initial and final dyspnea and efficacy scores were calculated. These results may help facilitate incorporation of the dyspnea protocol into nurse case management techniques utilized with end-stage COPD patients and will help address the issues of dyspnea and self-efficacy that these patients face.

**Review of Literature**

A comprehensive review of the literature examining disease self-management, or case management of COPD patients at home, was completed. The Medical Subject headings (MeSH) used in the search were: COPD, palliative care, disease management and self-management. Databases accessed in this search were: CINAHL, PubMed and Cochrane. The initial search yielded 24 articles. Studies were excluded if they were older than 2003, not written in English, focused on self-management in areas other than chronic illness or were expert opinions. Inclusion criteria included: studies within ten years or less from the date of publication, written in the English language, focus on dyspnea self-management in advanced/end-stage disease, quantitative and qualitative studies and systematic reviews. Ten articles met inclusion criteria. Of the ten studies, there was one observational study, six randomized controlled trials (RCTs), and three Cochrane reviews.

Gruffydd-Jones et al. (2010) conducted an observational study that examined the effect of nurse case management with COPD patients at high risk of hospital admission using home visits and phone calls. The results were non-significant reductions in the number of exacerbations, hospital admissions and bed days. However, there was an increase in both patient disease knowledge and self-efficacy. Bischoff et al. (2012) performed a blinded RCT looking at long-term effects of comprehensive self-management and routine monitoring of COPD patients’
quality of life, management of exacerbations and self-efficacy. The researchers found that quality of life did not show long-term benefits over the control group. However, patients in the self-management group demonstrated greater patient efficacy in managing COPD exacerbations than the control group. Zwar et al. (2012) conducted a blinded randomized controlled trial, looking at whether a case management model of home care for patients would improve outcomes for COPD patients. A nurse specializing in COPD disease management visited participants from the intervention group at their homes. An individualized care plan was developed for each patient in the intervention group. The study found that there were no significant results in disease-related quality of life; yet, patient knowledge and efficacy were statistically significantly higher.

A multicenter RCT by Bourbeau et al. (2003) showed more positive results in favor of self-management programs. The intervention was comprised of a comprehensive patient education program administered through weekly visits by trained healthcare professionals over two months combined with monthly telephone follow up. The study found that hospital admissions for COPD exacerbations, emergency visits and unscheduled physician visits were reduced. Health-related quality of life scores also improved after four months. The study concluded that a self-management program run by a trained professional could significantly reduce service utilization and improve health status. Studies containing general chronic illness self-management programs, including COPD, were also included in this literature review. Aiken et al. (2006) conducted an RCT that examined chronic illness management in COPD and congestive heart failure (CHF) patients within a hospice setting. The researchers used the “PhoenixCare intervention”, which provided integrated case management for patients with end-stage COPD or CHF and was overseen by a palliative care provider, but managed by the patients’
regular healthcare network. A designated nurse case manager provided care. The RCT results showed that at six months, the intervention group had an improved level of patient education.

Chronic illness was also the focus of two other RCTs, Homing in on Health (HIOH) (Jerant, Moore-Hill & Franks, 2009) and the Care Transitions Intervention (CTI) (Coleman et al., 2006). The HIOH program was a chronic disease self-management program geared toward increasing patient self-efficacy through home visits or by telephone contact by trained health workers. The results showed that HIOH delivered by in-home visits resulted in higher illness management efficacy at six weeks and six months. The CTI analyzed data from 750 patients in one community, with 11 selected chronic conditions, including COPD. The intervention patients were identified at time of hospitalization. The intervention provided support during the care transition occurring after discharge home from the hospital, focusing on decreasing rates of re-hospitalization. Intervention patients received home visits and telephone calls from advanced practice nurses, or transition coaches. The intervention patients had lower re-hospitalization rates than the control patients. The results were statistically significant for decreased hospitalizations at 30 days and 90 days.

Three systematic Cochrane reviews were included in this literature review. In the first Cochrane review, Effing et al. (2009) reviewed 14 randomized and non-randomized controlled trials looking at COPD self-management programs. These studies showed a significant decrease in the rate of hospital admissions and a small but significant decrease in patient dyspnea. No significant effects were found in number of ER visits, doctor visits, or COPD exacerbations. In the second Cochrane review, Jeppesen et al. (2012) focused on Hospitals-at-Home. In the Hospital-at-Home, COPD patients who would have ordinarily been cared for in the hospital are cared for at home by a special respiratory nurse and overseen by a medical respiratory team.
This study was included as it involved in-home care of advanced COPD patients and was therefore relevant. Eight RCTs were included in the review. The combined data from the studies showed significant reductions in patient hospital readmissions for COPD exacerbations. Lower mortality rates for hospital at home patients were observed but results were not statistically significant. Using nursing telehealthcare with COPD patients showed similarly promising results. In the third Cochrane review, McLean et al. (2012) analyzed ten RCTs using telehealthcare, which included nurse case management through phone and video conferencing. The researchers found that using telehealthcare caused a clinically significant increase in quality of life and a clinically significant reduction of emergency department visits and hospital admissions.

The articles that were reviewed showed a clear consensus in favor of nurse case management in COPD patients at home. Positive study outcomes were seen with lower rates of hospitalization; higher rates of patient education. However, efficacy and palliation through study methods and outcomes varied widely. None of the studies that were examined utilized COPD dyspnea protocols or the dyspnea protocols were not reported. Regardless, all of these studies showed short-term patient improvements, which is appropriate for an end-stage COPD hospice population, as their prognosis is terminal and lifespan is six months or less. Despite the broad range of methods and outcomes, all of the articles concluded that nurse case management with COPD patients was a worthwhile intervention, especially in terms of short-term results.
Conceptual Framework

The Health Belief Model (HBM) appears most applicable to the COPD palliation program, as the focus of the program is palliation of dyspnea through patient behavior change induced by program participation. The HBM is one of the first theories of health behavior, formulated in the 1950s and revised in the 1990s (Rosenstock, Strecher & Becker, 1994; National Cancer Institute, 2005). The HBM looks at people’s motivations to change behavior; specifically, it outlines six needed factors for behavior change: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy (Rosenstock, Strecher & Becker, 1994; National Cancer Institute, 2005). These factors are then taken into account when designing short-term and long-term behavior modification programs.

The COPD Dyspnea Palliation Project was a short-term program, based on the HBM, designed to change end-stage hospice COPD patients’ perception of their disease and ability to control the dyspnea associated with the disease through nursing case management and patient education. The focus of the project was the palliation of severe dyspnea in adults with end-stage COPD. The project was designed to help these patients monitor and treat their dyspnea effectively with a step-by-step protocol, rather than ignoring or ineffectively treating their dyspnea, which may lead to severe respiratory distress. Using the HBM as the framework, the perceived threat was the patients’ perception of the severity of their illness and their risk of having acute dyspnea. The intervention was a combination of nursing case management and patient education around disease management and a dyspnea protocol. This intervention addressed the perceived benefit, reduction of dyspnea and increase in self-efficacy for these patients. Patient demographics were the major factor in influencing the level of patient self-efficacy in successfully producing the desired outcome, patient comfort and palliation of
symptoms. Perceived barriers were the ability of the patients to effectively monitor their condition in order to be able to utilize the intervention appropriately and the ability of the patients to proceed with the interventions outlined by the COPD palliation program. Financial barriers were the cost of additional equipment and medication not covered by hospice. Cues to action to prompt utilization of the project protocol were increasing dyspnea and decreasing patient efficacy.

**Project Description**

**Purpose**

The purpose of the COPD Palliation Project was to effectively reduce dyspnea and discomfort in end-stage COPD home hospice patients through the use of nursing case management and a dyspnea algorithm taught to patients and their caregivers. The objectives and expected outcomes were:

1. To reduce or maintain patient dyspnea scores by using the modified Borg scale, with the goal being a Borg score of “2” or lower in 50% of the participants. Dyspnea was assessed during weekly telephone calls and Borg scale was reinforced. Dyspnea scores from the initial visit and final follow up call were analyzed for percent outcome improvements.

2. To assess weekly patient activity-related efficacy by using the modified MRC dyspnea scale, with the goal being an MRC score of “2” or lower in 50% of the participants. Breathlessness was measured in terms of patient activity levels. Weekly telephone calls were made to assess efficacy and reinforce the MRC scale. Efficacy scores from the initial visit and final follow up call were analyzed for percent outcome improvements.
Methods

Study Design

The intervention was case management with patient education and was offered to all enrolled hospice patients with a primary or co-morbid diagnosis of end-stage COPD. The project was a one group, pre and post-test design. There was no control group. Project approval was sought and obtained from the hospice agency’s Ethics Committee. Written consents for project participation were obtained from patients or their health care proxy (See Appendix H). Data was collected from subjects, but each subject was assigned a number and information was kept on a password-protected computer for security.

The COPD Palliation project combined case management and patient education to provide optimal patient dyspnea palliation and self-efficacy. Dyspnea treatment in this program was modeled after the dyspnea ladder utilized by Rocker et al. (2007). To manage end-stage COPD-related dyspnea, Rocker et al. (2007) developed a protocol to manage moderate to severe dyspnea called the dyspnea ladder. The first step on the ladder is utilization of bronchodilators, exercise and supplemental oxygen. With persistent or increasing dyspnea, the next step of the ladder is to be implemented. This step uses non-pharmacological measures, such as pulmonary rehabilitation, fan, relaxation techniques, pursed lip breathing and paced activities for dyspnea relief. With increasing dyspnea, palliative pharmacological measures such as morphine and anxiolytics need to be titrated until acceptable levels of dyspnea are reached. Rocker et al. (2009) suggests slow oral or parenteral opioid initiation, with titration until acceptable levels of dyspnea have been reached. Anxiolytics are suggested as a palliative medication in conjunction with opioids. Rocker’s use of opioids in the dyspnea ladder is well supported by current evidence, and has been shown to have good results with COPD-related dyspnea (Abernathy et al.,
2003; Jennings et al., 2002, Rocker et al, 2007), as well as greater self-efficacy. Improvement in self-efficacy is achieved through the decreased sensation of breathlessness, which can lead to an increased ability to perform activities of daily living.

In the COPD project, an algorithm for increasing dyspnea was taught to end-stage hospice COPD patients and their caregivers and was to be utilized when the patient was having an episode of worsening dyspnea. The algorithm is a modified version of the hospice’s respiratory program protocol, contains many of the components of Rocker et al.’s (2007) dyspnea ladder and was approved by the hospice Medical Director. In the project, the DNP student acted as a COPD nurse case manager and principal investigator and had oversight of the planning, implementation and evaluation stages of the project. The preceptor for the project was the hospice Director of Education and Organizational Integrity.

The DNP student enlisted the help of a research assistant, a hospice RN obtaining her Master’s degree in Nursing Clinical Leadership, to help with the initial home visits and follow-up. The DNP student and assistant met to go over project guidelines, expectations and expected outcomes. The DNP student and assistant were in continuous contact over the course of the project to ensure that both teaching and follow up methods were consistent. The student contacted patients who were eligible for the COPD Palliation Project in January of 2014 to schedule an initial home visit. The DNP student and research assistant then made an initial home visit to perform teaching around the dyspnea algorithm, obtained consent and gathered data on baseline patient dyspnea and efficacy. The patient’s assigned RN case manager and clinical manager were notified via email if the patient or caregiver agreed to be in the study. After the initial teaching, the DNP student and assistant followed up with four weekly telephone calls to measure and treat dyspnea per the algorithm, measure self-efficacy and provide ongoing
education. During the fourth call, the student and assistant obtained final dyspnea and efficacy scores in order to see if overall patient dyspnea and efficacy improved. The results were then analyzed and disseminated to the agency and written up in a capstone paper.

**Project Setting**

The community that was the focus of this project was end-stage COPD hospice patients in the North Shore and Greater Boston areas of Massachusetts. The patient catchment area in this intervention encompassed Norfolk, Essex, Middlesex and Suffolk counties. In Massachusetts, the rate of deaths from COPD per 100,000 people is almost double that of the nation (MassCHIP, 2010). According to MassCHIP (2010), Massachusetts rate of death from COPD is 86.9 per 100,000 people. The national rate is 44.7 per 100,000 people (CDC, 2011). Looking at the Healthy People 2010 initiative, the Chronic Disease Objective is to slow deaths from COPD among adults aged 45 and older to achieve a rate of no more than 60 per 100,000 people (NCHS, 2012). In these counties, rates of death per 100,000 from COPD ranged from 69.4 to 91.4 per 100,000 people, above Healthy People 2010’s goal and well above the national average (NCHS, 2012). According to the CDC’s demographics (2011), adults in Massachusetts with COPD were more likely to have COPD if:

- They were aged 65 years or older.
- They were female.
- They were unable to work.
- They had not graduated from high school.
- They had a household income of less than $25,000.
- They were divorced, widowed or separated.
- They had a history of smoking.
They had a history of asthma. Among residents of Massachusetts, the age-adjusted percentage of residents diagnosed with COPD was 5.4% in 2011 (CDC, 2013). Looking at the evidence, it is clear that the communities being examined warranted more awareness with regards to end-stage COPD symptoms and management of those symptoms, especially dyspnea. At this time, there is no statewide protocol for COPD management.

The COPD Dyspnea Palliation Project targeted patients with end-stage COPD within the 600-patient average daily hospice population located on the North Shore and within the Greater Boston communities. Care Dimensions (CD), formerly Hospice of the North Shore and Greater Boston, was chosen as the site for this project due to the availability of end-stage COPD patients. End-stage COPD patients comprise approximately 10% of the patient population of the agency. The micro community consists of the COPD patients, their family, caregivers and the hospice teams assigned to the patients. The hospice team consists of the RN case manager, social worker, chaplain and hospice physician. The hospice RN case manager directs patient care and leads the treatment team. Social worker and chaplains lend support to the patient and family. Hospice physicians are also an integral part of and oversee hospice care and assist in symptom management.

In October 2013, CD started a respiratory program for patients with end-stage pulmonary disease. Patients admitted to the hospice with end-stage COPD are eligible for the program, which provides a protocol for dyspnea management that hospice nurses use with patients in respiratory distress. The COPD Dyspnea Palliation Project took things a step further, providing education to home patients and caregivers so that they could utilize the protocol themselves, to achieve greater palliation and efficacy. The protocol for the project was similar to the dyspnea
algorithm used in the respiratory program, but modified for use by the patients and caregivers (See Appendix C).

**Participants and Sample Size**

The patients who participated in the project were hospice patients, with primary or co-morbid diagnosis of end-stage COPD, enrolled in hospice under CD. These patients met the COPD hospice criteria put into place by the National Hospice and Palliative Care Organization and Centers for Medicare and Medicaid Services’ (CMS) local coverage determinations. The CMS criteria for hospice for COPD patients are:

- The patient is oxygen dependent.
- The patient has a forced expiratory volume (FEV) of less than 30%.
- The patient has had one or more hospitalizations for COPD in the past year.
- The patient has had weight loss, cachexia or decreased functional status.
- The patient has co-morbid conditions shortening lifespan (Curtis, J., 2008).

The sample population for this project was a convenience sample from all enrolled home hospice patients with a primary or co-morbid diagnosis of end-stage COPD. The prognosis of the sample population was terminal, with six months or less to live. Nursing home and assisted living end-stage COPD hospice patients were excluded, as the project intervention could not be performed in these settings. The sample size was dependent on the number of end-stage COPD patients enrolled in hospice at the time of the study who consented to participate in the project. Out of a total of 62 patients identified from the record review, a total of 46 were selected as appropriate, based on the Medicare hospice COPD criteria. Of the 46 patients selected, 7 passed away, and 20 agreed to participate in the project.
Plan and Study Protocol

The project followed the Plan-Do-Study Act model (PDSA) (Speroff & O’Connor, 2004). A six-month timeline was needed for this project (See Appendix G). The project had five phases corresponding to the PDSA model. The first phase started in November of 2014 and lasted until January of 2014. The first phase involved planning for the implementation of the COPD Dyspnea Palliation Project. Elizabeth Robitaille, CD Director of Education and Organizational Integrity, agreed to precept the DNP student and signed the agreement form. Regular meetings were held with the CD preceptor and education staff to provide updates on progress and bring up any concerns or issues with the project. Final approval was given after acceptance of the project by the hospice Ethics Committee. The DNP student secured the help of another RN to act as a research assistant in the study and project tools were put into place. These tools included: methods of capturing current patients within the electronic medical record; providing necessary equipment and medications for these patients; and creating a modified dyspnea protocol to be used by the patient and caregivers. Using the hospice COPD protocol as a guideline, the DNP student created the modified protocol and approval was secured.

The second phase took place from January to February of 2014. During this phase, the identification of end-stage COPD patients eligible to participate in the COPD Dyspnea Palliation Project was accomplished. The DNP student reviewed hospice patient records and, using CMS COPD hospice guidelines, selected end-stage COPD patients to be included in the project. In the end, 20 participants were recruited to participate in the project. The RN case managers and clinical managers were notified of patient participation and study protocols were shared via email. The DNP student called the selected patients, or their caregivers, informed them of the project and asked for their cooperation. Once enrolled, the patient and student set up a time for
an initial home visit, which lasted 30-45 minutes. At the initial visit, patient and family project education was conducted, as well as obtaining written consent. Intensive teaching around the CD dyspnea algorithm was the emphasis of this project, with patient and caregiver verbal feedback and demonstration required to show understanding of project materials and goals. A baseline dyspnea score, using a modified Borg Scale, and a baseline activity-related patient efficacy score, using the MRC Dyspnea Scale, was assessed and recorded on an Excel spreadsheet.

The third phase, which took place from mid-February to the end of March 2014, was the actual patient implementation of the project. The DNP student and assistant called participants every week and asked them to rate their level of dyspnea, using the modified Borg Scale. **Modified** Borg scale scores were taken at the initial home visit and at the final follow up call. The group (n=20) was provided weekly education on the dyspnea protocol and scale by phone for four weeks. Patients and/or caregivers were also asked to score dyspnea during the weekly follow up calls made by the student and assistant to make sure that the patient or caregiver was using the scale accurately and to track progress and provide education.

The DNP student also utilized the MRC dyspnea scale to measure patient efficacy. The participants (n=20) were given education at the initial home visit on using the MRC scale. This was reinforced during the weekly follow up calls, where patients and/or caregivers were asked to score patient efficacy. **The dyspnea algorithm was utilized to mitigate any dyspnea symptoms. If the algorithm was ineffective, the DNP student immediately contacted the patient’s RN case manager and clinical manager for further interventions, such a call to the patient by the RN case manager, an MD consult about the patient or a nursing visit made to the patient.** The weekly phone call also served as a time to reinforce patient education and note any questions or issues.
regarding the COPD treatment plan. The dyspnea assessments and continuing patient education were designed to meet project goals of dyspnea palliation and increased patient self-efficacy.

The fourth phase, took place from the end of March to mid-April of 2014, concluded the data collection and results were analyzed. The student contacted each of the project participants by phone, to assess a final dyspnea and patient efficacy score. At this time, the student asked participants for feedback about patient outcomes and the study. The student then reviewed the dyspnea and efficacy data and analyzed the outcome measures. The data analyses were based on defined goals and outcomes for this project. Two objectives were evaluated in this dyspnea palliation project; a reduction in dyspnea using a modified Borg Scale and an increase in efficacy measured by a modified MRC scale. For both objectives, mean, standard deviation and percentage outcomes were calculated using Excel 2011. The analysis outcomes and feedback were then compiled to present in a report. All data analyses were reviewed with the CD Director of Education and Organizational Integrity.

The fifth and final phase, will conclude in June of 2014, and will consist of the project evaluation. A meeting will be held with the Director of Education and Organizational Integrity to discuss study results and the implications for current end-stage COPD hospice patients. A meeting will also be held with the Ethics Committee in June of 2014 to report on the results of the study. Future modifications to the CD respiratory program will be discussed at this time. The ongoing evaluation plan recommended for the respiratory program will be to recommend annual audits for monitoring COPD patient dyspnea and efficacy and respiratory program evaluation through the hospice education department.
Agency Support and Materials

In looking at the dominant paradigm of providing comfort care to patients with life-limiting illnesses, the stakeholders to be engaged were: the CD management team, the Board of Trustees, the CD employees, as well as the patients and families served by the agency. The beneficiaries were: the CD RN case managers, patients and their families. As hospice care generally treats the patient and family as a unit, the clients are the patients and families served by CD. In meetings with the CD Chief of Executive Operations, Diane Stringer and the Director of Organizational Integrity, Elizabeth Robitaille, about the COPD Palliation Program, they both made it clear that CD was fully committed to supporting this project (See Appendix D). The organization was very supportive and was very interested in the results of this project. The CD Director of Organizational Integrity acted as a preceptor for the DNP student, and the student utilized CD staff educators, as well as other key staff and resources in completing this project. The DNP student reported project updates at the beginning, middle and end of the program to the agency and doctoral committee. The plan going forward is to utilize these results in the modification of the agency respiratory program.

The costs for this project were related to patient education and data collection. The student and CD provided the key resources and materials needed for this project (See Appendix F). Education staff, patient population, medical records, hospice protocols, electronic medical record, computer and cell phone were provided by CD for the DNP student’s use. The CD education department staff members, medical records staff members, home care team nurse case managers and clinical managers all facilitated in the implementation of this project. The student provided all travel expenses, writing materials, and study protocol materials to be distributed to patients and caregivers. The student provided laminated COPD Dyspnea Protocols, Modified
Borg Scales and Modified MRC scales, along with the patient consent forms to participate in the study, to each of the participants.

Results

Data Analysis

Categorical data were analyzed to describe the population based on demographic data (See Appendix H). The project participants represented 16 different towns from the agency service area with the geographic radius of approximately 60 miles. Of the participants (n=20) in the project, nineteen (95%) were white and one (5%) was Asian. Thirteen (65%) participants were women and seven participants (35%) were men. The age range of the study participants was 48 to 101 years of age. The mean age of the participants was 80.65 years of age, with a standard deviation of 12.74.

Patient Dyspnea Self-Management

The first goal of the COPD Dyspnea Palliation Project was to maintain or reduce patient dyspnea to a Borg scale score of “2” (slight dyspnea) or lower in 50% of the project participants. The data for the dyspnea pre and post-test were graphed (See Appendix J). Of the total sample size (n=20), none of the participants were following a dyspnea protocol prior to the study. The pre-test mean score was 2.15, with a standard deviation of 1.63. The post-test mean score was 2.10 with a standard deviation of 1.80. At the initial home visit, 11 participants (55%) reported Borg score of “2” or lower. At the final follow up, 15 participants (75%) reported a Borg score of “2” or less. The project goal of having 50% of the participants report Borg scores of “2” or less at the post-test was met.
Impact on Patient Efficacy

The second goal of this study was to improve patient efficacy by maintaining or reducing MRC scale scores to “2” (short of breath with housework or activity) or lower in 50% of the participants. MRC scale scores were taken at the initial home visit and final follow up call. The pre-test efficacy score was taken during the initial visit, the post-test score was taken at the final follow up call. The data from the pre and post-test efficacy were graphed (See Appendix K). The efficacy pre-test mean was 2.80, with a standard deviation of 1.01 and the efficacy post-test mean was 2.95, with a standard deviation of 0.71. At the initial home visit, 6 participants (30%) had an MRC scale score of “2” or lower. At the final follow up call, 5 participants (25%) had an MRC scale score of “2” or lower. The project goal of having 50% of the participants report MRC scores of “2” or less at the post-test was not met.

Discussion

The COPD Dyspnea Palliation Project looked specifically at end-stage dyspnea patients in a hospice setting to improve comfort and function. The study findings indicated that the COPD Dyspnea Palliation Project is effective in improving dyspnea outcomes for end-stage dyspnea patients. This may have been because patients and caregivers were more aware of dyspnea and the methods to palliate dyspnea. Patients and caregivers appreciated having a dyspnea protocol to follow and also appreciated the follow up phone calls, as a chance to discuss their condition and ask questions. By the end of the study, 75% (N=15) of the study participants reported that they were fairly comfortable in managing their symptoms related to dyspnea.

Patient efficacy did not improve; in fact, patient efficacy decreased from pre-test to post-test. The most likely reason for this is the fact that the patients in this project were categorized as being terminally ill and identified as end-stage COPD hospice patients. As these patients were
on hospice, they were declining in function and condition. Though dyspnea may be controlled as a symptom, patient function at this point of care is unlikely to return to any great extent, regardless of comfort level. End-stage COPD, patients are taught to conserve energy and rest, not exert themselves, which leads to increased shortness of breath. An observation made during home visits was that many of the patients in the study verbalized the need to have daily routines in place to compensate for decreased function and how uncomfortable they were in making any changes. For the reasons stated, patient efficacy was not affected by this study. These findings suggest that end-stage COPD patient efficacy cannot be evaluated by measures such as an improvement in patient activity or the ability to complete activities of daily living. Instead, patient efficacy could be defined as patient knowledge and comfort with disease management for this patient population. Future studies could also include measures to evaluate family caregiver efficacy in managing patient breathlessness.

During follow up calls, patients relayed information regarding the use of opioids and benzodiazepines, mainly Morphine and Lorazepam (trade name: Ativan), for dyspnea and although this information was not included in the study objectives, it was helpful in understanding the study results and so has been included in the discussion section. Further research and analysis of the use of benzodiazepines in conjunction with opioids would be of great benefit.

**Patient Morphine Usage for Dyspnea**

An important finding of this project was that COPD patients were reluctant to use morphine for respiratory distress. Patient Morphine use during the study was noted during weekly follow up calls. Of the participants (n=20), 7 (35%) used Morphine for dyspnea. During the follow up calls, 7 (35%) participants reported that instead of using Morphine first as the
“rescue medication” per protocol, they used Lorazepam first with good effect. Seven (35%) participants and/or caregivers reported that they were uncomfortable using Morphine and did not want to use it for respiratory distress. This finding indicates the need for further education and reinforcement in use of Morphine for dyspnea. Further analysis may conclude that using Lorazepam as the first “rescue medication” would benefit some patients, especially those prone to high anxiety, more so than using Morphine first. If patient breathlessness and tachypnea were independent of anxiety, Morphine would remain the first “rescue medication” within the protocol. At this time, it appears that the participants are self-selecting in their use of Lorazepam and Morphine. This fact points to the need for the RN case managers, in conjunction with their end-stage COPD patients, to modify the dyspnea protocol to fit the associated symptoms for each patient. The protocol can easily be adjusted in this way. However, more research is necessary to evaluate the extent of the positive effects of Lorazepam in dyspnea and its placement within the dyspnea protocol.

**Potential Risks**

The potential risks of using opioids to treat end-stage dyspnea in COPD patients must also be addressed, as opioid use is incorporated into the dyspnea protocol utilized by the project. Research has shown that patients’ and physicians’ fear and discomfort with opioid use in treating dyspnea is a large barrier to providing effective palliative care for patients with end-stage dyspnea (Rocker et al., 2012). Patients often fear addiction, respiratory depression, sedation or death by opioid overdose, a fact that remains true for patients on hospice care (Rocker et al., 2012). Physicians often feel discomfort in prescribing opioids for end-stage dyspnea for the same reasons and may be inexperienced in dealing with its sedative effects, which are uncommon with low dose opioids (Rocker, et al., 2009). To combat this discomfort, Rocker et al.
(2009) suggested using a low-dose, slowly titrated approach to opioids in end-stage dyspnea, with close provider follow up to build confidence in both the provider and patient and to manage any side effects. The COPD Palliation Project takes this low dose, slow titration approach in its dyspnea protocol.

Jennings et al. (2002) examined opioid use in treating end-stage dyspnea in a systematic review. The researchers reviewed 18 RCTs that involved the use of oral or parenteral opioids to manage advanced dyspnea. This review found a statistically significant effect for both oral and parenteral opioids in the management of dyspnea. There was no evidence that use of opioids caused respiratory depression or a drop in oxygen level. The reported side effects, which included nausea, vomiting, drowsiness, dizziness and constipation, were typical of opioid use and self-limiting. There were six reported cases of opioid withdrawal syndrome after stopping opioid use. There were no reported cases of death due to opioid use. Prophylactic treatment with anti-emetics and laxatives were sufficient to eliminate most of the side effects. Despite reluctance of both patients and providers to use opioids to treat dyspnea, recent data showed that patients with end-stage dyspnea had significant benefits with opioid use in end-stage COPD dyspnea with few adverse effects

Limitations

The study had some built in limitations. The hospice model already uses a case management model and team approach for all patients, thereby providing general support with symptom management. In working within a population that already operates within a case management model, it may appear that the results may have been enhanced by enrollment within a hospice setting. As all patients on hospice services receive equivalent case management services, regardless of diagnosis, the effect on clinical outcomes for this project would be
negligible, if any.

The project time frame presented a significant limitation. The project was implemented and evaluated in a three-month time frame, which affected both sample size and results. The critical status of the patients and the high rate of patient demise before the end of the study was also a consideration. Seven of the selected participants died before the project was implemented; four of the participants died within a few days of study completion. A significant sample size was difficult to maintain. COPD patient census and admission of patients with COPD varied from week to week, again affecting sample size. Another consideration was that input from both patients and caregivers were considered in this study, which may have skewed results. Participant and/or caregiver assessment of dyspnea and efficacy was subjective and their use of the scales and protocol was not consistent. To address this issue, the DNP student and assistant reinforced and re-taught patients and caregivers how to use the dyspnea protocol, Borg and MRC scales during weekly follow up calls.

As with all studies, patient and employee buy-in were key considerations. Though RN case managers were notified of the project, if their patients were included in the study and given the study protocols, there was very little interest shown in the study. With RN case manager support and reiteration of study protocols, patient outcomes may have shown greater improvement.

However, despite limitations, the collaboration with CD staff in implementing this project, obtaining feedback and discussing possible modifications of the existing respiratory program were all critical steps in the continuation of the interventions implemented by this capstone project. The COPD Dyspnea Palliation Project is an important initial step in the creation and standardization of a COPD palliative care protocol and will likely provide important
insights about nursing case management of end-stage COPD patients upon future review and evaluation.

**Conclusion**

As discussed earlier in the paper, a standardized COPD palliation protocol remains to be established. Design, methods and goals vary widely, due to the lack of an established COPD protocol. Clearly, there is a need from the patient care perspective, as well as from a research perspective, to organize and create a national or state protocol for increased dyspnea palliation for end-stage COPD patients. Nurse case management is just one suggested method in dealing with the ever-increasing numbers of COPD patients and their associated symptoms. The intervention of case management was evaluated by a thorough literature review, the results of which show that relatively few studies have been done, all differing in methods and objectives. The studies that were analyzed showed short-term positive effects in patient education, efficacy and palliation, thus supporting the benefit of future research on nurse case management outcomes in treating end-stage COPD patients.

The addition of a dyspnea protocol, coupled with nursing case management of chronic and end-stage illness will likely be a more viable, longer-term model for palliation of COPD symptoms. Percentage outcome improvements were shown with dyspnea levels with the COPD Dyspnea Palliation Project interventions, which suggest greater levels of palliation with protocol-based management. Ongoing work and evaluation will need to be done to continue to assess the study protocol effects on COPD-related dyspnea levels. There will be ongoing work based on the study design through the CD’s Respiratory Program. Close monitoring of these patients and the effects of the protocol will need to occur in order to create standardized best practices around comfort and palliation of end-stage COPD patients.
References


Coleman et al. (2006). The Care Transitions Intervention: Results of a
Randomized Controlled Trial. *Archives of Internal Medicine, 166*(17).


Pinnock, H., Kendall, M., Murray, S., Worth, A., Levack, P., Porter, M...
Doi:10.1136/bmj.d142.


Appendix A

Rocker’s Dyspnea Ladder

(This is the dyspnea ladder as described by Rocker et al, 2007. Traditional methods, such as bronchodilators are the first step with increasing dyspnea resulting in opioid and anxiolytics use.)
Appendix B

The Modified MRC Breathlessness Scale

<table>
<thead>
<tr>
<th>Grade</th>
<th>Degree of breathlessness</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not troubled by breathlessness except with strenuous exercise. At baseline</td>
</tr>
<tr>
<td>2</td>
<td>Short of breath when doing housework or any activity.</td>
</tr>
<tr>
<td>3</td>
<td>Short of breath when walking from room to room, needing to stop and rest</td>
</tr>
<tr>
<td>4</td>
<td>Short of breath in going from bed to chair, or toileting.</td>
</tr>
<tr>
<td>5</td>
<td>Too breathless to be able to leave the bed.</td>
</tr>
</tbody>
</table>

## Appendix C

**Care Dimensions Respiratory Program Patient Protocol**

| Step 1 | • Position patient upright  
• Oxygen titration  
• Relaxation techniques  
• Assess |
| --- | --- |
| Step 2 | • Open window and set up fan  
• Administer Duoneb  
• Reassess |
| Step 3 | • If no relief with duoneb, administer morphine, 5-10 mg PO/SL once.  
• **Call CD immediately after morphine administration. Ask to speak to triage RN (978-774-7566)** |
| Step 4 | • If no relief in 15 minutes, administer morphine 5-10 mg PO/SL (2nd dose) |
| Step 5 | • If no relief in 15 minutes, repeat duoneb  
• Administer Lorazepam 1 mg PO/SL once |
| Step 6 | • **Call CD to report status of patient and for further instruction (978-774-7566).** |

(CD Policies and Procedures, 2013)
Appendix D

Letter of Agreement

University of Massachusetts Amherst
School of Nursing – Graduate Program
Student-Preceptor-Faculty Agreement

Course # 898A

The preceptor agreement permits nursing students of the School of Nursing, University of
Massachusetts Amherst to participate in a student preceptorship in your facility.

Hospice of the North Shore & G. Boston
(Clinical Site Name) Please print

Conditions of this program are as follows:

The Affiliation period will be: November 2013 to May 2014

The student, Karen Ray

Will be under the supervision of Elizabeth Robitaille acting as preceptor.
(Preceptor Name)

of the School of Nursing serves as the liaison with Professor Jeungok Choi.

your facility for the above course(s).

Preceptor Responsibilities:

1. Read Preceptor information supplied by the student.
2. Function as a role model in the practicum setting.
3. Facilitate learning activities for no more than two students per day.
4. Orient the student(s) to the practicum site.
5. Collaborate with faculty to review the progress of the student toward meeting practicum learning objectives.
6. Provide feedback to the student regarding practicum performance.
7. Contact the faculty if assistance is needed or if any problem with student performance occurs.
8. Discuss with faculty/student arrangements for appropriate coverage for supervision of the student should the preceptor be absent.
9. Give feedback to the nursing program regarding practicum experience for student and suggestions for program development.

Agency Responsibilities:

1. Retain ultimate responsibility for the care of clients or the maintenance of programs.
2. Retain responsibility for preceptor's salary, benefits, and liability.

Page 1 of 3
University of Massachusetts Amherst
School of Nursing – Graduate Program

Confirmation of Student-Preceptor-Faculty Agreement to Clinical Preceptorship

University of Massachusetts Amherst, School of Nursing – Student

Kaveni Roy
(Print)  

11/11/13
(Date)

Preceptor/Clinical Agency

X  Elisabeth Robitaille
(Print)  

1/1/15/13
(Date)

University of Massachusetts Amherst, School of Nursing - Clinical Faculty

Site Name: Hospice of the N. Shore & G. Boston

Site Address: 75 Sylvan Street

City, State, Zip Danvers MA 01923

Location Phone #: 978-774-7524

Email: Fax:

Curriculum Vitae or Resume Required with this Form.

Please return this signed form and your CV or Resume by mail to: Maureen Bailey, School of Nursing, University of Mass, 651 North Pleasant Street, Amherst, MA 01003-9299.

Preceptor will receive the following documents:

- Course Outline and Evaluations Tools
- Preceptor Handbook
- Copy of Signed Preceptor Agreement

Revised 7/20/09
Appendix E

Modified Borg Scale for Dyspnea

Instructions for Borg Dyspnea Scale

Use this scale to rate the difficulty of your breathing. It starts at number 0 where your breathing is causing you no difficulty at all and progresses through to number 10 where your breathing difficulty is maximal.

How much difficulty is your breathing causing you right now?

<table>
<thead>
<tr>
<th>0</th>
<th>Nothing at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Very slight</td>
</tr>
<tr>
<td>2</td>
<td>Slight</td>
</tr>
<tr>
<td>3</td>
<td>Moderate</td>
</tr>
<tr>
<td>4</td>
<td>Somewhat severe</td>
</tr>
<tr>
<td>5</td>
<td>Severe</td>
</tr>
<tr>
<td>6</td>
<td>More Severe</td>
</tr>
<tr>
<td>7</td>
<td>Very severe</td>
</tr>
<tr>
<td>8</td>
<td>Very very severe</td>
</tr>
<tr>
<td>9</td>
<td>Extremely severe</td>
</tr>
<tr>
<td>10</td>
<td>Maximally severe</td>
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</table>

(Borg, G., 1982)
## Appendix F

Table 1. COPD Palliation Project Budget

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<th></th>
<th>Student Contribution</th>
<th>Agency Contribution</th>
<th>Total Cost</th>
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</thead>
<tbody>
<tr>
<td>Case Manager (student)</td>
<td>$0</td>
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<td>$0</td>
</tr>
<tr>
<td>Agency Oversight of Project</td>
<td>$0</td>
<td>($5000) 5% of staff time in one year</td>
<td>$0 (time donated by agency)</td>
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<tr>
<td>Materials (pens, paper, lamination)</td>
<td>$300</td>
<td>$0</td>
<td>$300 (student contribution)</td>
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<tr>
<td>Travel (gas, mileage)</td>
<td>0.55cents/mile * 50 miles * 20 = $550</td>
<td>$0</td>
<td>$550 (student contribution)</td>
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<tr>
<td>Equipment (Computer, fax, copy machine)</td>
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<td>($200)</td>
<td>$0 (agency contribution)</td>
</tr>
<tr>
<td>Phone usage</td>
<td>$0</td>
<td>($100)</td>
<td>$0 (agency contribution)</td>
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# Appendix G

Table 2. Project Timeline

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<th></th>
<th>Nov</th>
<th>Dec</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
<th>Apr</th>
<th>May</th>
<th>June</th>
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<tr>
<td>Select study participants</td>
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<td></td>
<td></td>
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<tr>
<td>Planning</td>
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<td>X</td>
<td>X</td>
<td></td>
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<td>Pre-test</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
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<tr>
<td>Implementation of intervention</td>
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<td>X</td>
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<td>Post-test</td>
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<td>Data analysis</td>
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<td>Evaluation</td>
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<tr>
<td>Dissemination of results</td>
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<td>X</td>
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</table>
Appendix H

INFORMED CONSENT RELEASE

Investigator:

My name is Kaveri Roy, and I am a Care Dimensions hospice nurse and a graduate student at the University of Massachusetts, Amherst. I am inviting you to participate in a research study. Involvement in the study is voluntary, so you may choose to participate or not. I am now going to explain the study to you. Please feel free to ask any questions that you may have about the research; I will be happy to explain anything in greater detail. Suzanne Furgal, a Care Dimensions hospice nurse and a graduate student at Curry College, will be assisting me in this study.

I am interested in learning more about COPD. My study is called the “COPD Palliation Project”. In this project, you and your caregiver(s) will be asked to look at a COPD hospice protocol and talk about your experience with the disease. This will take approximately 30 minutes of your time. After that, either Suzanne or I will call once a week for four weeks to see how you are doing, check on your shortness of breath and your activity level. This will be a brief phone call and you are welcome to ask any questions or share concerns at this time. All information will be kept anonymous and confidential.

The benefit of this research is that you will be helping us to understand COPD-related shortness of breath. This information should help us to better understand and treat dyspnea symptoms for all of our COPD hospice patients. There are no risks to you for participating in this study. If you do not wish to continue, you have the right to withdraw from the study, without penalty, at any time.

Participant - All of my questions and concerns about this study have been addressed. I choose, voluntarily, to participate in this research project.

print name of participant

signature of participant ____________________ date ____________________

print name of investigator

signature of investigator ____________________ date ____________________
Appendix I

Demographic Characteristics of the Study Participants (N=20)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Age</th>
<th>Gender</th>
<th>Race</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>N</td>
<td>Percent</td>
</tr>
<tr>
<td>Age</td>
<td>80.76 (12.74)</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>48 to 101</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>65%</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>35%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Comparison of Patient Dyspnea Scores (Modified Borg Scale) Between Pre and Post Test

**Pre-test Dyspnea (percentages by Borg score)**

- 0: 25% (5 patients)
- 1: 10% (1 patient)
- 2: 20% (2 patients)
- 3: 20% (4 patients)
- 4: 20% (5 patients)

**Post Test Dyspnea (percentages by Borg score)**

- 0: 20% (2 patients)
- 1: 5% (1 patient)
- 2: 50% (3 patients)
- 3: 15% (8 patients)
- 4: 5% (1 patient)
Appendix K

Comparison of Patient Efficacy Scores Between Pre and Post Test

**Pre-Test Efficacy (percentages by MRC scale)**

- 1 (15%)
- 2 (15%)
- 3 (45%)
- 4 (25%)

**Post-Test Efficacy (percentages by MRC scale)**

- 1 (10%)
- 2 (15%)
- 3 (40%)
- 4 (35%)