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Integration of Palliative Care for Improving Quality of Life in Patients with Chronic Obstructive Pulmonary Disease

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Integration of Palliative Care for Improving Quality of Life in Patients with Chronic Obstructive
Pulmonary Disease

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Abstract

The purpose of this scholarly project is to determine if the integration of palliative care into COPD management provides an improvement in symptom burden associated with quality of life and end of life care when compared to the standard of care. A review of the literature was performed using the following electronic databases, and the use of keywords and mesh terms were used to define the set of literature that would be critically analyzed. A total of 16 articles achieved the necessary criteria for review and critical assessment. The literature reviewed various aspects related to symptom burden and symptom management associated with the disease, advanced care planning documentation, integration of palliative home care, and challenges surrounding integrating palliative care into standard care plans. The data shows that there was little statistical support for integrating palliative care to improve quality of life through more appropriate management of symptom burden associated with the disease. The literature did find support for the addition of palliative home care for improvements in advanced care planning. The scholarly project concluded that more research is needed to truly assess if palliative care has increased benefits in COPD management because there continues to be challenges that surround the integration of this specialty.

Keywords: Palliative Medicine, Palliative Care, Advanced Care Planning, Pulmonary Disease, Chronic Obstructive, Quality of Life

Introduction

Chronic obstructive pulmonary disease (COPD) is a significant cause of mortality and morbidity across the globe. The Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease report (2020), indicates that the disease was responsible for more than 3 million deaths in 2012. The primary causes of COPD include genetic pre-disposition, cigarette smoking, or exposure to toxic environmental and occupational factors. COPD is often characterized by periods of stability interspersed with exacerbations. As the disease progresses over time, the duration between these periods usually decreases, eventually ending in death. As the disease progresses, COPD causes deterioration of lower airway structures leading to symptoms such as chronic cough, dyspnea, and sputum production. Many of the symptoms associated with COPD are frequent reasons for seeking medical treatment in the primary care setting. The Global Initiative for Chronic Obstructive Lung Disease (GOLD) (2020) uses a combined assessment score to categorize disease progression. The severity of airflow limitation is staged through a graded scale I-IV based on the forced expiratory volume (FEV₁) obtained during spirometry. The “ABCD” group system is used to categorize exacerbation risk. This combined assessment score is used to help guide treatment plans for patients based on recommendations set forth by the GOLD criteria. The GOLD criteria are used as the standard of care in the management of symptoms associated with COPD. As the disease progresses in severity, these symptoms can be extremely distressing for the patient and the caregivers, leading to a decrease in quality of life (Duenk et al., 2017; Higgins et al., 2014; Long, Bekelman, & Make, 2014; Marx et al., 2016).

Originally founded to assist with end-of-life care and decision making for patients with terminal cancer, palliative care aims to provide a holistic approach to managing symptoms

associated with severe illnesses. Currently, the addition of palliative care services can be applied at any stage of a disease, terminal or not (Lanken et al., 2008). For patients and caregivers, the goals of palliative care aim to improve quality of life, provide emotional support, prevent suffering, and aid in advanced care planning opportunities (Lanken et al., 2008). As patients with COPD near the end of life, integrating palliative care should be considered for the improvement of quality of life by managing symptoms and focusing efforts on the decision-making surrounding end-of-life planning.

Statement of the Problem

In the later stages of COPD, *GOLD Stage III-IV*, chronic symptoms cause breathlessness, social isolation, depression, and anxiety, leading to decreased quality of life (Global Initiative for Chronic Obstructive Lung Disease, 2020). The symptom burden of the disease is comparable to lung cancer near the end of life, yet patients with COPD are less likely to receive palliative care services (Bloom et al., 2018; Wysham, Cox, Wolf, & Kamal, 2015). There is evidence to suggest that the integration of palliative care into the treatment plan for COPD patients can provide more appropriate management of both psychologic and physical symptoms. Through integrating palliative care earlier in disease progression, it is hypothesized that patients and their care providers may see an increase in quality of life towards the end of disease progression.

Research Question

Does the integration of palliative care in COPD management provide an improvement in symptom burden associated with quality of life and end of life care when compared to the standard of care?

Methods

A review of the literature was performed using the following electronic databases; Pubmed, Embase, CINAHL, Dynamed Plus, and Cochrane Library. The use of keywords and mesh terms were used to define the set of literature discussing COPD and the integration of palliative care. The literature was further refined for common themes associated with palliative care within the treatment plan for COPD patients. The search was performed to include articles within the last five years. The search revealed a total of 297 articles between all the databases searched. Multiple studies were excluded because they accepted patients less than 18 years of age. Additional studies were excluded because they only had an abstract available, resulting in insufficient information about the study. A total of 23 articles initially met the criteria for critical review and analysis. Many of these articles were comprehensive literature reviews and were not utilized because they lacked original research. The preliminary research trials that were necessary for inclusion fell outside the original five-year period. The search period was expanded from the last five years to 15 years. When the search was expanded, 16 articles achieved the necessary criteria for review and critical assessment.

Literature Review

It is theorized that palliative care should be standardized as part of care for end-stage COPD. Research within the last 15 years suggests that the use of palliative care in managing COPD patients is underutilized. It continues to be limited by factors surrounding the disease process of COPD, an understanding of when physicians should recommend palliative care and comprehension of palliative care goals.

The Burden of Chronic Obstructive Pulmonary Disease

Patients with COPD often have a high symptom burden that is continually under-addressed. Symptoms include breathlessness, fatigue, pain and cough which increase as the disease progresses. The presence of anxiety and depression which are also associated with the disease can lead to a decrease in the quality of life for these patients. There is a vast quantity of literature supporting the addition of palliative care in the management of terminal lung cancer patients and it has been shown to improve the quality of life and symptom burden (Bloom, Slaich, Morales, Smeeth, Stone, & Quint, 2018). While the known benefits of palliative care exist in these terminal patients, there is little literature to quantify the benefits of palliative care in advanced lung diseases such as chronic obstructive pulmonary disease (COPD).

The first piece of literature reviewed was a cohort study by Bloom, Slaich, Morales, Smeeth, Stone, & Quint (2018), which aimed to address the use of palliative care support (PCS) in a primary care setting for COPD patients. The Bloom et al. study used an open cohort design that reviewed electronic healthcare records from 2004-2015. The database used to retrieve the dataset consisted of 674 primary care practices and 11.3 million patients. Due to the extensive nature of the database used, the dataset covered a broad demographic of patient populations. The primary outcome tracked in this study was the documentation of PCS. Associations between secondary variables and palliative care support were calculated using logistic regression. Secondary variables to be compared included: GOLD stage, smoking status, sex, age, history of lung cancer, depression, anxiety, body mass index (BMI), number of exacerbations during the year before the trial, and medical research council dyspnea score (MRCd). Linear regression was also used to compare secondary variables between the sample cohort and patients that were deceased patients during follow-up from the original group.

There was a total of 92,365 patients included in the study cohort. During the follow-up period, 26,135 (28.3%) patients of the cohort had died. The data results demonstrated that only 7,198 (7.8%) of patients out of the entire cohort had documentation of PCS through their primary care physician. In comparison, the percentage of deceased patients who had documented PCS was 21.4%. For patients who had died of COPD with a co-diagnosis of lung cancer, the results showed an increased likelihood of receiving PCS (1,764 of 23,014; 56.5%). The percentage of patients who died with only the diagnosis of COPD were found to receive PCS merely 16.7% (3,831 of 23,014). The study also concluded that patients with only a COPD diagnosis who were referred to PCS had less time remaining and thus were less likely to benefit from its services (6-12 months: risk ratio 1.3, 95% CI 1.1–1.6; $p < 0.01$; 1-6 months: risk ratio 1.4, 95% CI 1.3–1.7; $p < 0.0001$). During 2005, PCS was only initiated in 1.2% of patients, compared to 2014, which showed the use of services increased to 16.5%. This statistic demonstrated more than a 10-fold increase in the amount PCS offered to COPD patients over the years.

Even though Bloom et al. (2018) was limited by challenges surrounding quantifying end-stage COPD and the use of a quality control program that motivated providers to record PCS, it is still essential for this scholarly project. The study consisted of a large cohort and spanned a diverse group of demographics. It concluded that while PCS services were offered to patients with COPD, they were provided later in the disease process and utilized less frequently than patients with lung cancer.

The second piece of literature was a multi-regional cross-sectional survey by Ding, Small and Holmgren (2017), that aimed to compare how clinical treatment delivered by physicians matched patient stance on symptom burden in treating their COPD according to the GOLD criteria. According to GOLD (2020), the primary goals in managing patients with COPD include

evaluating current symptoms to improve quality of life, preventing hospitalizations, and lowering the risk of future exacerbations. Many patients with COPD fail to meet COPD treatment goals with pharmaceutical management set forth by the GOLD criteria (Ding, Small & Holmgren, 2017). It is suggested that the clinical practice of prescribing does not follow the guidelines recommended by GOLD, and that practice does not meet the patient's expectations of how they think their disease is being managed (Ding et al., 2017).

Inclusion criteria for physicians included holding a current license to practice for a minimum of five years and being responsible for at least three or more patients with COPD. Patient inclusion criteria included a diagnosis of COPD confirmed with spirometry and successful completion of the COPD Assessment Test (CAT). The CAT score was used to quantify symptom burden. The patients were then placed into GOLD classification groups, A-D, according to the GOLD criteria (Ding et al. 2017). A total of 903 physicians and pulmonologists participated, with a total of 1,641 patients.

The two groups associated with the highest symptom burden were GOLD classification groups B and D. Patients that fell into groups A and D (61.5% and 77.5%) were treated most appropriately according to the treatment criteria set forth by GOLD. Patients in group B and C were more likely to have their treatment misaligned and mismanaged when compared to the recommendations set forth by the GOLD criteria (<40%). The study also found that patients in group D were the most likely to receive treatments aligned with GOLD recommendations. Interestingly, the mean CAT score was 20.4, meaning that most of the patients participating in this study had indicated a high level of symptom burden (>80%). Ding et al. concluded that with routine care, a high symptom burden remained among patients even with treatment. The results suggest that there is a consistent misalignment between GOLD recommendations and patterns of

prescribing.

One limitation of this study was the potential cost differences and availability for medications across countries that were not accounted for, making it possible that some of the required pharmaceuticals were unavailable. When this study was published, the 2017 GOLD report amended the ABCD classification system. Patients were classed as high risk based only on exacerbation history. In contrast, the data from this study used the 2014 GOLD report for classification of groups, which classified patients as high risk based on airflow limitations or exacerbation history. The use of two different variables to classify patients allows for more misclassification among the groups. The Ding et al. is vital because it shows that even with routine care according to the GOLD criteria, patients with COPD are still experiencing high symptom burden. It demonstrated inconsistencies that exist in provider prescribing even when using standard care. The research further discusses that the addition of palliative care could potentially decrease high symptom burden in patients who are provided with appropriate treatment.

The next study by Marx et al. (2016), organized a qualitative longitudinal study using semi-structured interviews to explore what it was like for patients to live with COPD. This study assessed the patient's perspective of their disease and how it affects them daily. Marx et al. found that COPD is a disease often misunderstood by patients after they receive the diagnosis, and there is a lack of education and communication about the disease duration and progression. Given the disease's unpredictable nature, the continued burden of COPD on the patients goes beyond respiratory dysfunction and includes psychological issues. Through patient conducted interviews, Marx et al. hoped to gain insight into what it means to live with an incurable disease, and how through these gained perspectives, providers may help patients cope with their illness

more appropriately through addressing other psychosocial needs.

The study used semi-structured interviews that were held every four months over a year. The initial meeting allowed the patient to tell their story in a narrative format with guided questions. Grounded theory was used to analyze the data set. All patients were designated stage III or IV according to GOLD criteria in 2010. Other inclusion criteria included breathlessness at rest or with slight physical exertion and frequent hospitalizations. There were 17 participants in the sample set with interviews taking place in patients' homes, in-hospital stays, or clinic visits.

Through the interviews, the results of this study concluded that many patients struggled with accepting the disease. Patients often described trying to maintain daily living up until the point when the disease hindered that ability. When the inability to maintain their daily lifestyle transpired, patients were often left feeling socially isolated and alone. Another conclusion drawn from the data set found that patients lack knowledge of disease progression and the inability to be cured. The physician's failure to clearly define the disease for the patients left them responsible for clarifying it alone. The study did positively show that patients felt that standard treatment and medications allowed them to control their symptoms accordingly and did not feel there needed to be any improvement in therapies.

Marx et al. had several limitations due to the small geographic region in which the study was conducted, allowing for potential bias from the population base. The use of "grounded theory" allowed the researchers to reconstruct how the patient was feeling during the conversation, while the use of qualitative data enabled the interpreters to add in their own bias regarding these patients' feelings leading to inconsistencies in data gathering. There was also difficulty gathering a representative sample. It also lacks significant statistical analysis that would prevent the addition of interpreted bias into the study.

The last piece of literature reviewed was by Wysham, Cox, Wolf, and Kamal (2015), who published a study regarding the discrepancies between the addition of palliative care services in patients with lung cancer and those with chronic lung disease. This study acknowledges that palliative care can be applied alongside current treatments to improve quality of life and decrease symptom burden for patients living with chronic obstructive lung disease (Wysham, Cox, Wolf & Kamal, 2015). The study's main objective was to compare the symptom burden of the two diseases at the time of the first palliative care consult and the proposed outcome would help highlight the need for better symptom management in patients with chronic lung diseases.

Wysham et al. (2015) used descriptive statistical analysis data collected from the Carolinas Palliative Care Consortium's Quality Data Collection Tool, which is gathered from palliative care practices in the southern United States. During patient encounters, providers of palliative care would use the system to record data associated with demographics, primary diagnosis for palliative care consultation (lung cancer, COPD, or pulmonary fibrosis), quality of life, tolerability of symptoms, estimated prognosis for survival, and interventions provided. Secondary variables in its data set include the completion of advanced care planning activities and completion of McGill Quality of Life Questionnaires. Symptoms quantified in this study included pain, dyspnea, anxiety, and depression. The variables were statistically analyzed using Kruskal-Wallis testing and χ^2 tests.

The study identified 238 patients referred to palliative care with a primary diagnosis of chronic lung disease or lung cancer between 2012 and 2014. There were 152 patients with a primary diagnosis of cancer and 86 patients with chronic lung disease, with 86% of the chronic lung disease patients having a diagnosis of COPD. At the initiation of the study, both groups reported a fair quality of life (QOL) at 54%. Interestingly, among the sample cohorts, patients

with chronic lung disease were more likely to have been hospitalized once within 30 days ($p < 0.0001$). Of the symptoms analyzed, pain and dyspnea were the most prevalent, and these symptoms did not statically vary between the cohorts ($p = 0.08$). Chronic lung disease patients were more likely to receive their first consultation with palliative care in the ICU (17% vs. 6%; $p = 0.005$). During this study, data collected found that there was a statistical difference between the cohorts having advanced care directives on file. Even with a prognosis of higher than 6-months, patients with chronic lung disease who received palliative care had advanced care planning documented almost two-times more frequently than lung cancer patients (62% vs. 32%; $p < 0.0001$).

The study from Wysham et al. demonstrated that there was no statistical difference in symptom burden between cohorts when comparing chronic lung disease and lung cancer. It also shows that chronic lung disease patients have been receiving their first palliative care consults during acute incidents, as demonstrated by the statistic discussing consult in ICU vs. outpatient settings. Overall, lung cancer patients appear to benefit from palliative care services across the span of their disease course. This reference is countered by the use of palliative care in COPD as a focus of end-of-life care and advanced care planning, with less regard to improving symptoms.

Limitations of the Wysham et al. research included the use of data from a site used for quality improvement, allowing for bias in favor of variables that needed to be improved. The data also combined COPD and pulmonary fibrosis into the chronic lung disease group, although most patients presented with COPD. The study cohort also placed patients into groups according to the primary diagnosis, which does not account for the possibility of lung cancer patients having COPD. Wysham et al. was also one of the only studies that included women. The vast majority of other research included for this project was represented by only males in study

cohorts. This research is beneficial because it analyzes the symptom burden experienced between patients with lung cancer and chronic lung diseases, demonstrating that these patients have comparable symptoms at the time of consult to palliative care.

Management of Symptoms

The discussion in the section above demonstrated that many patients with end-stage COPD experience a high symptom burden that can often be undertreated through conventional means. The addition of palliative care to help manage these symptoms may provide the necessary care that has been lacking, leading to the improvement of symptoms which may increase the quality of life. Early in the disease course, palliative care should be considered to alleviate symptom burden and address other psychosocial challenges associated with the disease.

The first piece of literature reviewed was a cluster-controlled trial by Duenk et al. (2017). The authors of this study wanted to assess the results of palliative care on the quality of life for patients with COPD. The study discusses advanced COPD and the negative impacts it has on patients' quality of life. Current literature supports early integration of palliative care in other life-limiting conditions such as cancer and heart failure; however, there is a lack of research surrounding its use for COPD (Duenk et al., 2017). Duenk et al. hypothesized that patients with COPD who received palliative care integrated with usual care would have improved quality of life, lower symptom burden, and fewer hospital admissions. The secondary hypothesis was that patients who received proactive palliative care are more likely to have documented choices made regarding an advanced care plan (ACP).

The interventional group would receive palliative care from a specialized palliative care team (SPCT) alongside routine care; the control group would receive usual care. Patients were selected based on a poor prognosis status after an acute exacerbation. The study used the St.

George Respiratory Questionnaire (SGRQ) to assess the quality of life at 3, 6, 9, and 12 months. After the first survey, the study also included secondary questions regarding readmissions, decisions about ACP, and survival. After the trial, there were 238 participants, 90 assigned to the interventional group, and 138 in the control group.

This research demonstrated that there was no statistical variance between the groups based on the SGRQ score (95% CI, $p = 0.70$), which demonstrated no change in the quality of life. At the completion of the trial, the group that received palliative care experienced less symptom burden associated with the disease ($p = 0.04$) and had more documented ACP choices ($p = 0.003$). All other secondary questions had no statistical differences among the groups. In regard to improvement in quality of life, this study did not support the hypothesis set by the authors; it does show support for their secondary hypothesis which included decisions around ACP. It concluded that with the addition of palliative care, patients were more clearly able to convey what they wanted towards the end of life.

The next piece of literature reviewed was a single-blind randomized control trial constructed by Higginson et al. (2014) to assess patients with advanced disease and refractory breathlessness. Breathlessness is the most common symptom associated with advanced COPD and other pathologies, such as lung cancer (Lanken et al., 2008). Breathlessness is a subjective experience that includes distinctive features, varying in intensity, that places a considerable symptom burden on the patients who experience it (Higginson et al., 2014). As the disease progresses, this symptom becomes resistant to conventional treatment, leading to worsening anxiety and fear of breathing compromise. The objective was to evaluate the integration of early palliative care and respiratory services in the treatment plan to help manage patients with

breathlessness. The study hypothesized that patients receiving support from the breathlessness service would have better skills to manage breathlessness than patients receiving standard care.

This six-week interventional study included patients that were randomly assigned to the intervention or control group through the Kings Clinical Trial Units online randomization system. The intervention group had a care team, known as the breathlessness support service, that included palliative care. The service provided an initial assessment of the patient and a breathlessness package that provides nonpharmacologic tools and a "crisis plan" for symptom management. The control group received the usual care. An at-home assessment took place at week two, and a follow-up appointment was held at week four. The primary variable assessed would be mastery of breathlessness. To quantify the data received during interviews, the researchers would use the Chronic Respiratory Disease Questionnaire to determine the quality of life. At the end of the six weeks, 83 patients remained. The primary variable statistics were assessed using the Student's *t*-test, sensitivity analysis, and analysis of covariance (ANCOVA).

Higginson et al. found that patients in the interventional group had significant mastery of their breathlessness compared to the control group (mean difference 0.58, 95% CI 0.01-1.15, $p = 0.048$; effect size 0.44). Sensitivity analysis by ANCOVA was found to be similar. The secondary variables analyzed in the study had no significant differences between the intervention and control groups. Higginson et al. determined that there was a significant difference in survival for both groups in the trial (generalized Wilcoxon 3.90, $p = 0.048$). The results showed that 42 patients in the intervention group had all survived after 180 days. The control group started with the same number of patients ($n=42$) but found that after 90 days, four were deceased, and only 32 remained at 180 days. This a noteworthy finding and suggests that the addition of palliative care

can decrease mortality. Following the trial's completion, the patients in the interventional group reported less breathlessness than those in the control group.

One limitation surrounding Higginson et al. was that the study was only run over a six-week period, possibly skewing the data regarding the survivability. The study was not blinded, and because patients were aware of the group they were placed in, there was a potential to create bias. It also included data from other disease processes, which would restrict some of its feasibility to the research. Although Higginson et al. used data collected from other disease processes, it still has relevance to this research. The significance of adding palliative care to help manage patients with refractory breathlessness reveals the benefits that these services can have on the management of symptoms. It also demonstrated that the addition of these services could impact the quality of life through better symptom management and increase survivability.

The last study in the review of symptom management was a single-arm, longitudinal, mixed-method pilot study created by Long, Bekelman, and Make (2014) that focused on the feasibility and usefulness of palliative care by using advanced care practice nurses (APN) to manage dyspnea, anxiety, and depression in end-stage COPD. They hypothesized that through the integration of palliative care, patients would see an overall improvement in the quality of life due to improved management of these symptoms

Enrollment of symptomatic patients through inclusion criteria for the study included patients with advancing COPD, GOLD criteria stage III or IV, and the use of the Modified Medical Research Council (MMRC) Dyspnea Scale. The intervention for the study would be to integrate an APN specialized in providing palliative care to follow up and treat symptoms of anxiety, depression, and dyspnea for three months. Treatment plans were individualized according to the patients' needs and their responses to the following surveys: Patient Health

Questionnaire (PHQ) 9, Generalized Anxiety Disorder Scale (GAD) 7, MMRC, and the St. George Respiratory Questionnaire. The noted symptoms would be managed through nonpharmacological and pharmacologic methods. The data collected over the three months were analyzed using matched-pairs t-tests.

At the conclusion of the study, a total of 13 participants remained. All patients in the study used nonpharmacologic methods for treatment, and ten patients used opioids to manage their dyspnea. Patients with significant depression and anxiety were offered anxiolytics or antidepressants, and all refused these pharmacological treatments. After the first interview, Long et al. found that participants had a decrease in their anxiety and depression. Interestingly, this was due to a decrease in dyspnea, according to the patients. This trend continued for all subsequent interviews. However, there were no statistical differences between pre and post-study survey measures (St George Respiratory Questionnaire, $p= 0.2$; PHQ, $p= 0.096$; GAD, $p= 0.17$, MMRC 2). A total of 11 patients (85%) stated that they felt an improvement in their quality of life and wanted to continue palliative treatment.

A limitation of the Long et al. study was the small sample size. This small size cannot be used as significant evidence because it has the ability to sway the reader to believe the conclusions drawn may be more substantial than they genuinely are. Another limitation was that it did not use any type of comparison leading to biased data in favor of the hypothesis. The study cohort only included white males, which limits its applicability because it does not cover other demographics. While Long et al. does not have a significant study cohort, it does show promising results for future research. The patients who participated in this study reported that the integration of palliative care helped to better manage their symptoms related to dyspnea,

depression, and anxiety. In turn, the gains lead to an increase in quality of life, one of the primary treatment goals of palliative care.

Advanced Care Planning

The trajectory of illness in patients with advanced COPD is difficult to predict because it is progressive and highly individualized (Gainza-Miranda et al. 2019). Although it is recommended that a team-based approach may help guide these patients as they near the end, literature discussing the efficacy of this approach is lacking. Gainza-Miranda et al. (2019) conducted a prospective observational cohort study of end-stage COPD that compared the addition of a palliative home care team (PHCT) to usual care. The objective of the study created by Gainza-Miranda et al. was to analyze patients' survival after the initiation of PHCT and indicate what the end of life needs were for these patients. They hypothesized that the team-based approach would provide more appropriate end of life care.

The PHCT was composed of pulmonologists, palliative care specialists, and the primary care physician who would work together to provide care to the patient. Patients included in the study were referred by their primary care physician to be monitored by the PHCT. The intervention group would receive regular clinical care and be monitored monthly for up to two years by the PHCT. The primary variable calculated was survival time from the date the patient was included in the study until the date of death. The end of life descriptors recorded and analyzed included date and place of death, cause of death, the addition of palliative sedation, and implementation of advanced care planning (ACP). The symptom burden was assessed at every home visit using the Edmonton Symptom Assessment System (ESAS) and the Modified Scale of the Medical Research Council (MMRC) dyspnea scale. The St George Respiratory Questionnaire (SGRQ) was used to assess the quality of life at the initial and subsequent visits. The length of

time survived was reported with a confidence interval of 95%. Differences in hospital and emergency department admissions before and after the addition of the PHCT were analyzed using a dependent t-test.

A total of 60 patients participated over three years, with a median survival rate of 8.3 months from the introduction into the study. A total of 42 patients (70%) were deceased at the end of the study, with 36 (85%) dying at their homes or palliative care units. The leading cause of death in the patients was respiratory failure (93%). Dyspnea was the most common symptom that required the use of palliative sedation (83%). None of the deceased patients had implemented ACP at the beginning of the study, but 55% had performed ACP during follow up visits. Results from this study found that in a follow-up visit at three months, patients receiving palliative care continued to score high on the SGRQ despite continued disease progression. The involvement of the PCHT also yielded a statistically significant decrease in the number of admissions to the hospital ($p < 0.01$). The same was found to be valid for emergency department visits ($p < 0.01$).

Gainza-Miranda et al. research was limited by using a small group cohort that spans a significant time frame, which did not allow for a control group. Without a control group, a comparison could not be made, leading to biases and generalizations based on the results. The participants included in the study were mostly male, which has also been seen with other studies in this literature review. Without having a representative sample of females, it leads to a misrepresentation of demographics. Lastly, the majority of the participants had a lower level of education, which may infer a decreased ability to understand surveys and questionnaires necessary to assess secondary variables in the trial. The Gainza-Miranda et al. study is essential because it highlights the benefits of implementing a palliative care team in the treatment of

advanced COPD. Although not statistically significant over time, Gainza-Miranda et al. was able to demonstrate an improvement in the quality of life with disease progression.

To improve the quality of life for patients with advanced COPD, the Department of Pulmonary Diseases in Denmark constructed an outpatient service called 'Comprehensive and Prospective Treatment And Individual Nursing' (CAPTAIN) to integrate palliative care into end-stage COPD management. The program used a multi-disciplinary team of physicians and nurses to manage end-stage COPD cases, with the nurses primarily responsible for managing the patients. The objective of a study conducted by Bove, Lavesen, Jellington, Marsaa, and Herling (2018) was to collect data on the healthcare professional's perspective on how they expected the program to run and what their experiences were with the integration of the CAPTAIN program.

Bove et al. (2018) used qualitative data in the form of interpretive description (ID) gathered from the physicians and nurses who participated in the study. The period coined "pre" CAPTAIN was identified as the period before the program's implementation, and "post" was the time after the program began. Data analysis was achieved through a complicated method of interpretation and theme identification. The methodology described by ID was used for the analysis of the qualitative data collected.

In the pre-CAPTAIN phase, the healthcare providers conveyed worry and ambition. In discussions, during the pre-CAPTAIN period, the physicians' primary concern revolved around possessing the necessary skills to facilitate ACP conversations, due to a lack of education on the topic. Both physicians and nurses were optimistic that a team-based approach would allow for more open communication between providers and patients.

The post-CAPTAIN phase discussed the advantages and unintended consequences of the

program implementation. During post-CAPTAIN interviews, the teams saw an increase in positive patient experiences, but it also brought up consequences that were not expected. One of the most prominent themes was the increase of mental fatigue and stress that occurred among healthcare providers because of an increase in the complexity of patient encounters due to a decrease in the number of unnecessary appointments. The positive side of the program found that the physicians felt that this structure allowed them more time with the patients to honestly assess the needs and desires of their patients when it came to ACP. A nurse involved in the program stated:

What patients express immediately after ACP is that it was the best dialogue that they have had with their doctor for years because the focus was not on lung function. Focus was on their anxiety and fear of being resuscitated by an emergency hospitalization. (Bove et al., 2018, p. 6)

Bove et al. only discusses healthcare provider insight, which provided valuable information surrounding the adaptation of new programs such as CAPTAIN. It discusses the program structure's strengths, weaknesses and addresses issues that may not have been considered initially. One unexpected consequence was especially apparent when there was an increase in work-related stress and mental exhaustion because the patients' cases were highly complex to manage. One limitation of this program was the use of pulmonary physicians rather than PCPs, which may account for their concern regarding APC conversations. Bloom et al. (2018) found that PCPs are primarily responsible for the delivery of care in patients with COPD and they are more comfortable initiating difficult conversations.

The data obtained from the Bove et al. study found that while this new program improved quality of care and ACP in patients with advanced COPD, but it was countered by an increase in

work-related stress experienced by providers. This is important because it addresses healthcare professionals' needs when implementing new programs surrounding palliative care and complex patients. The CAPTAIN program was a new strategy that used a team-based approach to implement palliative care. With the addition of a healthcare provider perspective, it assisted in providing a framework of what was successful and where adjustments could be made for future projects. Evaluating experiences from the providers is key to a new program's success, and these viewpoints can help improve the CAPTAIN program and others to come.

In a study by Au et al. (2012), there is a discussion about the inadequacy of communication regarding the end of life care in patients with COPD. Outside research has demonstrated that patients prefer to have ACP discussions with their primary providers, but these discussions infrequently occur (Au et al., 2012). These conversations occur most often during acute exacerbations and the details most often involve conversations about "code status" without additional information about mechanical ventilation, medication administration, or pain management. The Au et al. objective was to critically assess if the use of a patient-specific feedback form provided to the clinician would increase the frequency and promote the quality of communication (QOC) regarding end-of-life care in an outpatient setting. The form provided was usually used by palliative care teams. The study's primary outcome would be to assess if the results of the intervention, the feedback form, improved the quality of communication. The secondary variable measured was the intervention effect on the likelihood of ACP communication with surrogates and clinicians.

This trial was executed as a clustered-randomized blind trial of patients and clinicians. It would include physicians and mid-level clinicians from primary care and chest clinics and their patients that were being seen for the management of COPD. The clinicians were randomly

assigned to either the intervention or control group. Both groups completed questionnaires before the trial to provide baseline data and gather the information for the feedback forms used in the intervention group. The intervention group would receive a patient-specific feedback form designed to help initiate conversations surrounding end-of-life care. Statistical analysis would include intention-to-treat regression analysis. When the outcome of the intervention was evaluated, it used cross-sectional estimating equation regression.

A total of 92 clinicians and 306 patients (151 intervention group, 155 control group) participated through the completion of the study. For both groups, the initial quality of communication was dismal. These values found for QOC did not change significantly with follow-up, and interestingly both groups displayed an increase in their scores. The secondary variable that assessed the outcome of the intervention on the likelihood the patient would discuss the end of life with their surrogate and clinician was statistically significant, with an absolute difference of 18.6% (unadjusted 30% vs. 11%; $p < 0.001$).

Limitations of this study showed a more significant number of patients that dropped out of the intervention group, which may have swayed the data towards the control group. Conduction of the study was through the Veterans Affairs hospital, which may have limited the study's generalizability because patients were not gathered from outside hospitals. Again there were no female participants, making their potential responses to the intervention unpredictable. The research conducted by Au et al. is vital to this literature review because it highlights that when patients provide feedback to their physicians regarding end-of-life care preferences, communication can be easily facilitated. It also demonstrates a need for more open communication between patients and providers. While this article does not explicitly discuss the use of palliative care, it can help support the theory that these programs help facilitate these

conversations, when backed by the other research completed for this project. The Au et al. study was the only one that included physician assistants in their data set. This is important because advanced care providers working alongside physicians provide valuable perspectives when it comes to discussions surrounding palliative care.

Integration of Palliative Home Care

Scheerens et al. (2020) determined that there was a void in research regarding the early integration of palliative home care (PHC) in patients with advanced COPD. While it is hypothesized that the early integration of palliative care into managing patients with advanced COPD is beneficial, there remains little concrete evidence to support this theory. The study produced by Scheerens et al. aimed to assess feasibility, acceptability, and effectiveness for integrating palliative care with the standard of care in a pilot randomized control trial over six months.

The methods for this controlled trial would randomly assign patients to either the intervention group, which integrated early palliative care alongside usual care. The control group patients would receive conventional treatment. The study employed palliative home care nurses (PHCN) to administer the care. The testing had five components that included training specifically for COPD management for the PHCN, visits from PHC every month, a pamphlet on how to cope with the disease and symptoms, care plans, and reporting mechanisms for the integration of PHC and usual care. The patients would be assessed on the outcomes from surveys conducted to determine changes in mood such as depression and anxiety, quality of life, symptom burden, and perceived quality of care.

The results yielded 39 patients after screening for inclusion criteria, with 20 in the intervention group and 19 in the control group. The statistics were analyzed using SPSS software

for the quantitative data, and interviews were conducted to yield the qualitative data. Concepts of acceptability, feasibility, and effectiveness were assessed based on the five components listed above. Effectiveness was measured using a mixed-model analysis between week zero (baseline) and week 24. Of the outcomes measured, the control group's hospitalizations were shown to differ significantly, which favored fewer hospitalizations in this group ($b = 1.85$; $SE\ 0.83$; $p = 0.03$). Perceived quality of care had significantly improved in the intervention group ($b = 0.56$; $SE=0.23$; $p = 0.06$). At week 24, there was also a difference between the two groups, with the control group reporting higher health-related quality of life than the intervention group. All other outcomes were unchanged and had no significant data to report. While this study determined that the intervention of PHC was feasible, the intervention's effectiveness did not produce the anticipated results, as there was no significance between the groups.

Limitations of the Scheerens et al. study was that the participants were informed about PHC, which may have led to selection bias because these patients would be more willing to accept this type of care. It was also not conducted blindly, and both groups were aware of their inclusion in the intervention or control group. Awareness of group participation could have led to biased reporting. Also, the PCHNs were previously trained to manage terminal cancer patients and only received a two-hour training on managing COPD patients before starting the study. The Scheerens et al. study did compare both qualitative and quantitative data from patients and health care professionals, which was a strength to this study.

A study by Janssens et al. (2019) hoped to determine the feasibility of palliative home care and its impact on admissions to the intensive care unit (ICU), emergency department (ED), and hospitals. It would compare the addition of palliative care over 12 months with usual care. It collected data from the previous year's hospitalizations of patients included in the study and

compared those with admissions over the trial period. The study also included the impacts of palliative care on anxiety, depression, health-related quality of life (HRQOL), ACP, and survival.

This randomized control pilot study took place over 12 months. Patients with severe COPD (GOLD stage III & IV) would be randomized to a standard care group (control) or the intervention group, which would receive usual care with the addition of monthly interventions by palliative home care specialists. The palliative home care team would spend time with the patients assessing symptom management, nutrition, provide patient education about COPD, discussion of social-spiritual needs, support interviews for caregivers, and conversations surrounding advanced care planning (Janssens et al., 2019). Groups were compared using the Mann-Whitney U test, Student's *t*-test, the Fisher exact or X^2 tests. Data were analyzed using Kaplan-Meier curves and log-rank tests. The study took into consideration the qualitative data from patient surveys regarding mood and HRQOL by mixed linear regression analysis and quantitative data that analyzed hospital, ED, and ICU admissions using incidence rate ratios.

A total of 49 patients were included in the study (23 in the control group and 26 in the intervention group). The results published by Janssens et al. found no statistical difference between the groups concerning hospital, ICU or ED admissions (hospitalization, $p = 0.219$; ED, $p = 0.484$; ICU, $p = 0.163$). The data also demonstrated that there was no statically significant difference between the groups concerning HRQOL, anxiety, depression, and survival scores. The authors also found that patients in the intervention group (35%) versus the control group (13%) had finalized decisions regarding advanced care planning ($p = 0.194$).

The recruitment process limited this study, and it had a difficult time reaching the desired number of participants. They also found that their inclusion criteria were more specific than

other studies previously published, which may have led to the insignificant data produced. The patients included also had a significantly impaired quality of life at the start of the trial, which may explain why there was no difference between the groups after the study. The research conducted by Janssens et al. is critical because it discusses potential problems regarding the integration of palliative care into the treatment of severe COPD. Although the study results did not support my research question and showed no significance between the groups, it highlights issues surrounding the initiation of palliative care, such as patient apprehension and denial of disease prognosis.

Buckingham et al. (2014) study evaluated the feasibility, acceptability, and the impact of extending palliative care to severe COPD patients. The study's objective was to apply palliative care needs through a nurse-led intervention group in patients' homes. The authors of the study created a program called HELPing older people with severe chronic obstructive pulmonary disease (HELP-COPD) to assess the objectives.

HELP-COPD trial was a 6-month feasibility trial that used a randomized (3:1 ratio) controlled trial format. The trial used qualitative and quantitative data to gather information and assess palliative care intervention for patients who were released from the hospital following an exacerbation. The nurse-led intervention group would include aspects of palliative care to manage COPD patients' physical and psychological needs over four weeks. The intervention would be compared to usual care. The trial used various questionnaires to evaluate the quality of life, physical well-being, and spiritual and psychological health. Interviews of healthcare professionals and patients were also conducted, allowing insight into how the HELP-COPD program was organized. Analysis of the interviews used the Normalization Process Theory. This theory critically critiques how the intervention might be applied to routine practice and if it is

feasible.

The results include 32 participants initially, with 24 randomly assigned to the HELP-COPD group. While the program was considered to have a positive impact on patients and professionals, it did little to address the majority of the expected needs. The pilot study did find that patients randomized to the intervention group were positive about their experiences concerning coping strategies related to their disease. General practitioners and nurses also found the application of the program an essential part of continuing to provide quality care to these patients. It also found issues surrounding the timing of when the intervention was applied and that there was a significant amount of overlap between the discharge plan in the usual treatment group when compared to the intervention group.

This study fell short of meeting the expected objectives. Patients that failed to complete the trail claimed the questionnaires were burdensome, which may have led to a small sample size. The Buckingham et al. study did not perform any formal statistical comparisons in the trail because they wanted to avoid inappropriate interpretation of the small data set. The pilot study results reflect that care applied post-hospitalization does little to help the patient through the disease's progression. It does highlight issues of integrating palliative care after an exacerbation that leads to hospitalization, and it discusses the need for integration sooner in the disease process, to assist in decreasing the likelihood of these events.

Challenges Surrounding Palliative Care Applications in COPD

The GOLD criteria (2020) recommends that palliative care be applied to patients with end-stage COPD towards the last years of life to improve symptom management and quality of life. One challenge surrounding the application of palliative care is predicting the disease trajectory. A study created by Bloom et al. (2019) aimed to create a tool that could be used by

primary care providers (PCP) to help predict mortality in COPD patients within 1-year. Previous models used to predict mortality were challenging to use and were meant to be used in specialty areas. Often PCPs are the healthcare professionals working closely with end-stage COPD patients and these predictive tools can be burdensome.

Data drawn from an electronic database containing health care records formed two participatory groups. The first cohort was randomized into test and training sets that were used to produce and validate the model, and the second cohort used an external dataset. The training set created a risk model, using Cox regression to predict mortality within 1-year based on a set of variables. The variables used for the model could be routinely collected by the PCPs and included "body mass index and blood results (B), age (A), respiratory variables (airflow obstruction, exacerbations, smoking) (R), and comorbidities (C)" (Bloom et al., 2019, p. 3). This model is referred to as the BARC index. After the BARC index was determined to be valid, it was compared to other prognostic predictability index models already employed in clinical practice. Index scores already in use included the body mass, index, obstructive, dyspnea, exacerbations (BODEx), dyspnea, obstruction, smoking, exacerbations (DOSE) and age, dyspnea, obstruction (ADO) (Bloom et al., 2019). A comparison of predictive capability between the index scores was plotted using characteristic curves and calculations to determine the area under the survival threshold curves.

There was a total of 54,990 patients that met inclusion criteria for the first cohort and 4,931 patients in the second cohort. The total number of variables assessed in the BARC index score was 18. The risk model was produced and determined to have a predictive performance that was acceptable. When compared to other index scores, BARC compared positively. The study concluded that one of the statically significant contributors to the model was the addition

of comorbidities and the authors highlighted the importance of including this variable into a viable index score. This study used patients within one year after they had an annual review for the first cohort, leading to selection bias, limiting some of the data available.

In conclusion, Bloom et al. (2019) determined that the use of the BARC index score could be used to predict one-year mortality in COPD patients better than other predictive index scores. The model created was more user friendly because the data used could be easily obtained in the PCP setting. The study created by Bloom et al. (2019) is essential to this research because it identifies one of the most significant issues surrounding palliative care's addition to end-stage COPD; the unpredictability of disease trajectory. Multiple index scores have been used to predict mortality within a year, but none of them have been statistically significant, and their use in clinical practice has not been a success. Bloom et al. demonstrated that the use of these services had expanded substantially over the years, but there is still work that needs to be done from a provider standpoint to encourage the addition of these services.

Scheerens et al. (2018) study was a portion of a more extensive phase 0-2 intervention trial called EPIC, which is currently collecting vast quantities of data surrounding the integration of early palliative care in patients with COPD. This trial of the EPIC study identified that there was little literature surrounding the opinions of general practitioners (GP) and home nurses (HN) regarding the early integration of palliative home care (PHC) in the management of end-stage COPD patients. This group of healthcare professionals is highly involved in the home and primary care of these patients. Their insight plays an essential role in providing valuable information about why there is difficulty surrounding this type of care in the management of end-stage COPD patients. This qualitative study's method included focused group interviews of GPs (n=28) and HNs (n=28). The group interviews focused on challenges surrounding PHC

integration early in disease trajectory and ways to ease the integration of PHC.

There were multiple challenges to the integration of care that were discussed. The first challenge was that COPD's disease trajectory is often unpredictable, making it difficult to determine when PHC should become integrated. They also determined that patients do not have a proper understanding of their disease, and they are in denial about how it will affect their quality of life. Lastly, communication between the healthcare professionals and the patient surrounding an understanding of palliative care prevented the initiation of PHC.

The Scheerens et al. (2018) study also found several factors that assisted in conversations about PHC integration. Hospitalization due to deteriorating condition or exacerbation, known as a "trigger moment," could help facilitate a conversation. Another was increased knowledge of PHC services for the caregiver and patients through increased education on the advantages of PHC. Advantages to PHC, such as advanced care planning, also aided in integrating these services into clinical practice. Lastly, improving communication between the patient and the healthcare professional helped educate the patient on the benefits of palliative care and improve their quality of life.

The use of focus groups limited this study by allowing for potential biases by the conductor of the interviews because the data collected was qualitative and open to interpretation. Lastly, some GPs who participated in the study had not admitted a patient to PHC within a year of the study, demonstrating a lack of experience when making these referrals. This study is crucial because it provides information from providers working directly with end-stage patients. The research provided by Scheerens et al. (2018) is critical to understanding the issues surrounding palliative care initiation into the management of patients with severe COPD.

Lastly, Almagro et al. (2017) created a robust systemic review of the current literature regarding the validity of suggested variables as prognostic indicators for the addition of palliative care in COPD. After a critical review of the literature, the authors would then apply the variables to a validation cohort to determine if these variables were appropriate for predicting one-year mortality in patients with COPD. The ability to predict one-year mortality would aid in the referral to palliative care alongside the standard of care.

The methods for the study used a three-phase approach. The first was to search the current literature and identify variables under consideration when deciding to add palliative care in managing patients with poor prognosis, which was survivability of less than one year. The second phase was to identify the association of the variables and one-year mortality from the original datasets. The last stage of the study would be confirmation of findings from the literature review with a cohort of COPD patients hospitalized due to an exacerbation. Statistical analysis for this project included mean and standard deviation (SD) analysis by ANOVA and Mann-Whitney *U* test for parametric data. A Chi-square test was used to assess qualitative data. Hazard ratio and 95% confidence intervals were calculated for survival time through Cox logistic regression analysis and the Kaplan-Meier survival curves. The area under the curve (AUC) regarding one-year mortality was further assessed and analyzed for specificity and sensitivity.

From the original 499 articles, 24 articles met the inclusion criteria for the study. These articles supplied the researchers with 20 variables used as poor prognostic predictors. The original materials were then ascertained, and relationships between the variables and one-year mortality were calculated. In the final phase of the study, a pooled cohort of 697 patients admitted and discharged from the hospital for acute exacerbation would complete a one-year follow-up to determine mortality. A total of 10 of the 18 variables critiqued in the validation

cohort met statistical significance for one-year mortality.

One limitation of this study was that the patients who were a part of the validation cohort had been recently hospitalized. Recent hospitalizations could be associated with a higher mortality rate than patients with COPD who were not hospitalized, which may have caused selection bias. The validation cohort also had significantly more male participants and cannot analyze gender differences and their role as a variable. Almagro et al. concluded that there were no prognostic variables statistically significant to predict one-year mortality in severe COPD. The critiqued variables were not a reliable way to predict the course of COPD and should not be relied upon for the initiation of palliative care. Through critical analysis of published literature and application to their validation cohort, the authors determined with confidence that the use of palliative care should not be based on the predictability of mortality.

Discussion

When patients with advanced COPD reach the end stage of the disease, it is known that many of these patients experience high symptom burden and low quality of life (GOLD, 2020). Patients with advanced COPD are candidates for palliative care, but their needs are often under met, and they struggle with impaired quality of life until their death (Bloom et al., 2018; Wysham et al. 2015; Higginson et al. 2014; Long et al, 2014). Palliative care uses a team-based approach to address various issues regarding symptom burden, psychological and spiritual aspects of patient and caregiver needs. The hope is that these services have the potential to increase the quality of life and more clearly define the disease of COPD.

The literature reviewed for this scholarly project has demonstrated that the symptom burden associated with this disease can decrease the quality of life as the disease progresses in severity. The research conducted by Bloom et al. (2018) and Wysham et al. (2015) demonstrated

that the burden of these symptoms is comparable to patients with lung cancer, yet COPD patients are less likely to be referred to palliative care. Ding et al. (2017) also found that the standard of care, which uses GOLD criteria to classify patients, does not equate to managing symptom burden appropriately. This supports the suggestion that while current treatments may be appropriate, patients still struggle with the symptom burden and there continues to be a missing piece in the management plan. Although Marx et al. (2016) was limited by its small data cohort and the use of qualitative data it did provide useful insight into patient perspective of the disease. The insight provided by the participants in the Marx et al. study demonstrated a need for more open communication between providers and patients for improved symptom burden.

Regarding to the management of symptoms, it was hypothesized that the research would provide support for the addition of palliative care. The articles reviewed found that while some specific symptoms such as breathlessness were found to statistically support the addition of palliative care, other articles did not agree with this finding. Support for the addition of palliative care was confirmed by Higginson et al. (2014), who demonstrated a statistical significance in favor of palliative care and symptom management. Results from Duenk et al. (2017), also supported this theory, which found that the addition of palliative care helped to better manage symptoms through decreasing the symptom burden; however, it did not improve the overall quality of life. Additionally, Scheerens et al. (2020), Janssens et al. (2019) and Long et al. (2014) research demonstrated that the integration of early palliative care did not impact the patients' overall quality of life.

As patients with severe COPD are near the end of life, the number of hospitalizations typically increases due to exacerbations (Wysham et al., 2015). The potential for death following these exacerbations increases, and although most patients prefer to die at home, they lack the

necessary documentation to follow through with these plans. The literature reviewed does support the addition of palliative care to aid in conversations regarding ACP. The articles demonstrated that patients were more likely to make ACP choices before death and were able to die at home or in palliative care units without invasive life-sustaining treatments (Gainiza et al. 2019; Janssens et al. 2019; Bove et al. 2018; Dunek et al. 2017; Wysham et al. 2015; Au et al. 2012). There is also a common theme that suggests the integration of palliative home care would reduce these hospitalizations through better management of symptoms (Janssens et al. 2019; Gainza-Miranda et al. 2019; Duenk et al. 2017). The statistical significance in the decreased number of hospital and ER admissions from Gainiza et al. (2019) supports the integration of a palliative care home team (PCHT) before the end of life. This was also supported by Duenk et al. (2017), who found that the addition of a PCHT did lead to decisions regarding ACP, and therefore, more desirable care towards the end of life. The most recent article published by Scheerens et al. (2020) does not support the hypothesis that palliative care could improve quality of life, and it did not produce the anticipated effects regarding the integration of palliative home care (PHC). This finding was also supported by Buckingham et al., who found that while PHC had positive benefits that were noted by both providers and patients, this data was not statically supported.

The majority of the articles reviewed pointed to various challenges surrounding the integration of palliative care in the management of COPD patients, even though it has been demonstrated that palliative care initiation can be integral in the management of other disease processes such as cancer (Bloom et al., 2018; Wysham et al., 2015). The Scheerens et al. (2018) study dives into various problems associated with the integration of palliative care. They found that patients often do not have an understanding of what COPD is and that the disease would

eventually end their life. The studies produced by Bloom et al. (2019) and Almagro et al. (2017) also recognize that there are no reliable methods to predict COPD mortality. Even though Bloom et al. (2019) was able to produce a prognostic predictability tool that has more clinical significance than previous ones used, these factors are only risk scores that can assist in making decisions about end-of-life care. This statement supports the continued discussion that disease trajectory is difficult to predict and the decision to add palliative care services should be based on clinical judgment and patient presentation. Another challenge surrounding the integration of palliative care is the lack of education provided to patients on the goals of palliative care. Many patients believe palliative care is the same as hospice care, which is applied when a patient has a prognosis of less than six months survival and is strictly end of life care. Providers should work to educate patients more frequently on the benefits that palliative care can provide, and these conversations should not focus on end of life, but rather improvement of quality of life.

The symptom burden associated with end-stage COPD can be distressing for the patients. Current literature to support the theory that palliative care can help to decrease this burden was limited, but there were a few studies that validated this hypothesis and highlighted the need for more research into the area. The majority of the published literature available is limited by very small cohort sizes and short follow-up periods. The use of small cohorts allows for the finding to be over or underutilized and may not be as conclusive when applied to larger trial groups. The research is also hindered by short follow-up times, given the unknown trajectory of the disease. The results may provide different outcomes and experiences if the treatment was applied sooner in the disease process rather than later.

In conclusion, this scholarly project has demonstrated that COPD has a high symptom burden that can be troublesome for the patients. While both standard of care and the addition of

palliative care can help to alleviate some of this burden and lead to an increase in ACP, the data does not fully support the integration of palliative care into the management of COPD patients. The addition of palliative into COPD patient management is still a relatively new area of medicine, and the benefits surrounding its integration into managing other disease processes besides cancer remains unclear. The current challenges that surround the integration of palliative care demonstrate that further research is needed to investigate how to work with these challenges and find a more appropriate way to introduce the topic of palliative care.

Clinical Application

There is strong support for the benefits of palliative care in patients with cancer, but the benefit of this service is lacking among patients with noncancer illness. Although the research surrounding the support of integration of palliative care into serious illnesses other than cancer is still limited, the clinician should be able to critically analyze if palliative care will improve the quality of life in patients with end-stage COPD.

The literature reviewed for this research project suggests that the addition of palliative care services may provide benefit to patients with life-threatening illnesses such as COPD. The data demonstrates that palliative care interventions, when compared with usual care, decreased hospitalizations and increased advanced care planning. It is important that providers recall that palliative care is not end of life care but provides a specialized focus to improve quality of life by addressing physical, physiological and social needs of patients and their families that align with other available treatment options.

While there may not ever be the “right time” to approach the subject of palliative care, it is critical for providers to analyze when the addition of palliative care may prove more beneficial than standard treatment alone. With the information provided in this research project, the

primary care provider working closely with the patient and their family, will have increased knowledge of this subject that will help recognize the need to add palliative care into the management plan of severe COPD. The number of palliative care specialists is limited when compared to the number of patients living with serious illnesses, which suggests that all clinicians should receive more generalized training in palliative care. As the population begins to age, more providers will be faced with the inevitable need to introduce palliative care principles to patients and their families.

References

- Almagro, P., Yun, S., Sangil, A., Rodríguez-Carballeira, M., Marine, M., Landete, P., Soler-Cataluña, J., Soriano, J., & Miravittles, M. (2017). Palliative care and prognosis in COPD: A systematic review with a validation cohort. *International Journal of Chronic Obstructive Pulmonary Disease* 12, 1721–1729. <https://doi.org/10.2147/COPD.S135657>
- Au, D., Udris, E., Engelberg, R., Diehr, P., Bryson, C., Reinke, L., & Curtis, J. (2012). A randomized trial to improve communication about end-of-life care among patients with COPD. *Chest*, 141(3), 726–735. <https://doi.org/10.1378/chest.11-0362>
- Bloom, C., Ricciardi, F., Smeeth, L., Stone, P., & Quint, J. (2019). Predicting COPD 1-year mortality using prognostic predictors routinely measured in primary care. *BioMed Central Medicine*, 17(1), 73. <https://doi.org/10.1186/s12916-019-1310-0>
- Bloom, C., Slaich, B., Morales, D., Smeeth, L., Stone, P., & Quint, J. (2018). Low uptake of palliative care for COPD patients within primary care in the UK. *European Respiratory Journal*, 51(2). <https://doi.org/10.1183/13993003.01879-2017>
- Bove, D., Lavesen, M., Jellington, M., Marsaa, K., & Herling, S. (2018). First-year experiences with a palliative out-patients structure for patients with COPD: A qualitative study of health professionals' expectations and experiences. *BioMed Central Palliative Care*, 17(1), 1–10. <https://doi.org/10.1186/s12904-018003690-2>
- Buckingham, S., Kendall, M., Ferguson, S., Macnee, W., Sheikh, A., White, P., Worth, A., Boyd, K., Murray, S., & Pinnock, H. (2015). HELPing older people with very severe chronic obstructive pulmonary disease (HELP-COPD): Mixed-method feasibility pilot randomised controlled trial of a novel intervention. *Nature Partner Journal Primary Care Respiratory Medicine*, 25(November 2014). <https://doi.org/10.1038/npjpcrm.2015.20>

- Ding, B., Small, M., & Holmgren, U. (2017). A cross-sectional survey of current treatment and symptom burden of patients with COPD consulting for routine care according to GOLD 2014 classifications. *International Journal of Chronic Obstructive Pulmonary Disease, 12*, 1527–1537. <https://doi.org/10.2147/COPD.S133793>
- Duenk, R., Verhagen, C., Bronkhorst, E., Van Mierlo, P., Broeders, M., Collard, S., Dekhuijzen, P., Vissers, K., Heijdra, Y., & Engels, Y. (2017). Proactive palliative care for patients with COPD (PROLONG): A pragmatic cluster controlled trial. *International Journal of Chronic Obstructive Pulmonary Disease, 12*, 2795–2806. <https://doi.org/10.2147/COPD.S141974>
- Gainza-Miranda, D., Sanz-Peces, E., Alonso-Babarro, A., Varela-Cerdeira, M., Prados-Sánchez, C., Vega-Aleman, G., Rodriguez-Barrientos, R., & Polentinos-Castro, E. (2019). Breaking barriers: Prospective study of a cohort of advanced chronic obstructive pulmonary disease patients to describe their survival and end-of-life palliative care requirements. *Journal of Palliative Medicine, 22*(3), 290–296. <https://doi.org/10.1089/jpm.2018.0363>
- Global Initiative for Chronic Obstructive Lung Disease (GOLD): Global strategy for the diagnosis, management, and prevention of Chronic Obstructive Pulmonary Disease. (2020, May 04). <https://goldcopd.org/>
- Higginson, I., Bausewein, C., Reilly, C., Gao, W., Gysels, M., Dzingina, M., McCrone, P., Booth, S., Jolley, C., & Moxham, J. (2014). An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: A randomized controlled trial. *The Lancet Respiratory Medicine, 2*(12), 979–987. [https://doi.org/10.1016/S2213-2600\(14\)70226-7](https://doi.org/10.1016/S2213-2600(14)70226-7)

- Janssens, J., Weber, C., Herrmann, F., Cantero, C., Pessina, A., Matis, C., Merlet-Viollet, R., Boiche-Brouillard, L., Stirnemann, J., & Pautex, S. (2019). Can early introduction of palliative care limit intensive care, emergency, and hospital admissions in patients with severe chronic obstructive pulmonary disease? A pilot randomized study. *Respiration, 97*(5), 406–415. <https://doi.org/10.1159/000495312>
- Lanken, P., Terry, P., Delisser, H., Fahy, B., Hansen-Flaschen, J., Heffner, J., Levy, M., Mularski, R., Osborne, M., Prendergast, T., Rucker, G., Sibbald, W., Wilfond, B., Yankaskas, J., & ATS End-of-Life Care Task Force (2008). An official American Thoracic Society clinical policy statement: Palliative care for patients with respiratory diseases and critical illnesses. *American Journal of Respiratory and Critical Care Medicine, 177*(8), 912–927. <https://doi.org/10.1164/rccm.200605-587ST>
- Long, M., Bekelman, D., & Make, B. (2014). Improving quality of life in chronic obstructive pulmonary disease by integrating palliative approaches to dyspnea, anxiety, and depression. *Journal of Hospice and Palliative Nursing, 16*(8), 514–520. <https://doi.org/10.1097/NJH.0000000000000111>
- Marx, G., Nasse, M., Stanze, H., Boakye, S., Nauck, F., & Schneider, N. (2016). Meaning of living with severe chronic obstructive lung disease: A qualitative study. *British Medical Journal Open, 6*(12), e011555. <https://doi.org/10.1136/bmjopen-2016-011555>
- Scheerens, C., Pype, P., Van Cauwenberg, J., Vanbutsele, G., Eecloo, K., Derom, E., Van Belle, S., Joos, G., Deliens, L., & Chambaere, K. (2020). Early integrated palliative home care and standard care for end-stage COPD (EPIC): A phase II pilot RCT testing feasibility, acceptability, and effectiveness. *Journal of Pain and Symptom Management, 59*(2), 206–224.e7. <https://doi.org/10.1016/j.jpainsymman.2019.09.012>

Scheerens, C., Deliens, L., Van Belle, S., Joos, G., Pype, P., & Chambaere, K. (2018). A palliative end-stage COPD patient does not exist: A qualitative study of barriers to and facilitators for early integration of palliative home care for end-stage COPD. *Nature Partner Journals Primary Care Respiratory Medicine*, 28(1).
<https://doi.org/10.1038/s41533-018-0091-9>

Wysham, N., Cox, C., Wolf, S., & Kamal, A. (2015). Symptom burden of chronic lung disease compared with lung cancer at time of referral for palliative care consultation. *Annals of the American Thoracic Society*, 12(9), 1294–1301. <https://doi.org/10.1513/AnnalsATS.201503-180OC>