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Increasing the Completion Rate of Advance Directives in Patients with Chronic Obstructive Pulmonary Disease in the Primary Care Setting Cynthia S. Davis Southern Illinois University Edwardsville

Increasing the Completion Rate of Advance Directives in Patients with Chronic Obstructive Pulmonary Disease in the Primary Care Setting

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a major cause of mortality and is the only cause of mortality that continues to climb (Reinke et al. 2016). Many patients diagnosed with (COPD) are unaware of the natural trajectory that the disease follows. According to Janssen, Engelberg, Wouters, and Curtis (2011) COPD has a trajectory that consists of gradual deterioration in functional status, that includes sudden and abrupt changes in condition due to life-threatening exacerbations that often require intensive care hospitalizations for mechanical ventilator support. The mortality rate within one year after hospitalization for an acute COPD exacerbation is 23%. Many patients with COPD have other co-morbid conditions that can further increase mortality. Due to lack of knowledge and planning, patients and families are often forced into making life and death health decisions while in midst of crisis. Lack of advance care planning negatively effects patients, families, care providers, and hospital systems. In adults with COPD, does the completion of advance directives decrease the likelihood of in-hospital death, unwanted aggressive treatment (intubation), improve quality of care (decrease emotional and physical harm to patient and family), and lower health care costs in the final week of life?

Aim

This literature review aims to identify important considerations when providing people diagnosed with life-limiting COPD an opportunity to be educated regarding the seriousness and trajectory of their illness, to voice their concerns safely in a supportive environment, to have their questions answered in a manner they can understand, and to be given the power to develop a plan of care that honors their wishes.

Search Strategy

The search strategy included Cochrane Database of Systemic Reviews, Cumulative Index to Nursing and Allied Health Literature Plus with Full Text (CINAHL), DynaMed, EBSCOhost, Medline-OVID Medline, and PubMed. Keywords for the searches were "DNR", "POLST", "COPD", "chronic obstructive pulmonary disease", ""end-of-life care", "advance care

planning", "COPD trajectory", "code status" "comorbidities of COPD", "provider order for lifesustaining treatment", and "intubation and COPD". The following review will define COPD, various forms of advance directives and the importance of having directives in place in order to increase quality of life, decrease symptom burden and unwanted aggressive medical treatment, and reduce costs of care.

Results

Integrative Review

The review of literature focused on the topics of pathophysiology of COPD, quality of life, decision-making, advance-care-planning, patient education, and patient understanding of illness.

Chronic obstructive pulmonary disease is categorized as an illness that causes

Pathophysiology of Chronic Obstructive Pulmonary Disease.

non-reversible airflow obstruction and an atypical inflammatory response in the lungs (MacNee, 2006). Even when noxious stimuli (smoke, dust, fumes) are removed, the inflammatory response continues. Inflammation results in airway edema, airway wall thickening, increased production of mucous and the paralysis of cilia, followed by increased obstruction of airflow with inhalation and expiration, which leads to hypoxia and hypercapnia (Battaro, 2017). Over time patients may develop pulmonary arterial resistance that can lead to pulmonary hypertension, cor pulmonale, and right-sided heart failure. The symptoms of COPD occur after the lungs are damaged and patients typically present with dyspnea, cough, and increased sputum production. Severity of COPD is assessed by use of spirometry which determines the ratio of a patient's forced vital capacity (FVC) and forced expiratory volume in one second (FEV1). Insert Stages of COPD here.

COPD is progressive, not fully reversible, and worsens over time despite medical intervention; meaning, COPD symptoms can be treated, but the disease cannot be cured. Patients who do not understand the trajectory of illness often feel frustrated and disappointed, which often leads to isolation and depression. Providing patients with knowledge gives them the ability

to forward think and prepare for the future. Patients cannot consider goals of care and advance care planning if they lack health literacy related to COPD

Patient Education and Assessment of Understanding

Patel (2011) reviewed, identified, and elaborated upon the importance of patient-clinician communication regarding trajectory of illness and end-of-life care. He found that discussions with patients regarding their understanding of COPD were scarce and the quality of the discussion was poor. Goldman (2017) describes a substantial lack of knowledge among the public about prevention, diagnosis, and treatment of COPD, especially by those who are at risk of or have already been diagnosed with COPD.

Research has found that many people who receive a diagnosis of COPD feel confused and misinformed, and the illness often goes undiagnosed among those at risk because they attribute their worsening symptoms to the aging process (Goldman, 2017). More concerning is the number of patients found to be lacking insight related to the chronicity of COPD and the awareness that a diagnosis of emphysema and chronic bronchitis is in fact a diagnosis of COPD (Goldman, 2017), thus leaving them ignorant of both appropriate treatment and ways to slow the advancement of disease.

In order to determine the patient's perception of COPD, Goldman and colleagues (2017) designed a phenomenological qualitative study to elicit in patients' own words their experience and understanding of COPD, and to further explore their perception of risk and how to live with the illness and corresponding symptoms. The main research question was: How do patients conceptualize the causes, symptoms, consequences, treatment and risk for developing COPD? A core list of multipart, open-ended questions was developed by reviewing published literature related to patients with a COPD diagnosis. The core questions centered around patient's beliefs, behaviors, concerns and perceptions. A chronic care theoretical model that focuses on support of the patient and caregiver through empowerment, was used.

The study revealed that patients who have experienced symptom burden and psychosocial stressors related to the diagnosis of COPD, benefit from having providers who help patients by offering educational materials that address gaps in care, who refer to COPD directly, and those who discuss denial of the correlation among COPD, asthma, bronchitis, emphysema,

smoking, and lifestyle (Goldman, 2017). As COPD advances, patients experience more frequent episodes of exacerbation in which symptoms suddenly worsen and hospitalization is often required. It is during hospitalization for exacerbation that patients are often asked if they would accept intubation should their ability to breath become more compromised. Patients who do not have advance directives often receive default invasive treatments, such as mechanical ventilation. Adequately preparing patients for increased symptom burden as lung function decreases, and providing reassurance that symptoms can be managed, is key to the development of individual, patient-centered goals of care.

Advance Care Planning

Simpson (2012) discussed the significant cost of COPD and projected by the year 2020, COPD would be the third leading cause of death in the United States. Simpson describes standard medical care for patients with COPD as episodic and targeted to relieve symptoms of exacerbation. Most care is provided in a hospital setting, despite increasing evidence that patients and family members needs are ongoing, experienced at home, and encompass psychosocial/spiritual as well as physical concerns. Given the fragmentation in care, Simpson went on to state that it is not surprising that discussions related to prognosis, illness trajectory and goals of care do not happen as they should, and currently the default in crisis is "do everything" when clinicians are unsure of how to proceed.

Conceptual Framework

Imogene King's Theory of Goal Attainment

Imogene King's Theory of Goal Attainment (Butts & Rich, 2018) is described as a philosophy of science that emphasizes wholeness and the interaction of elements within systems that occurs while the nurse and patient communicate to set goals that are mutually agreed upon and mutually achieved (Butts & Rich, 2018). The major concepts within the theory are comprised of

perception, self, image, interpersonal system comprised of interaction, communication, role and social systems made up of organization, authority, and power. King posited that when a transaction is made between nurse and patient, goals can be attained which will result in satisfaction. Communication is a concept in King's Goal Attainment Theory. The nurse should effectively communicate information so that patients can best set their personal healthcare goals as they relate to their health care situation. King applied her theory to the steps of the nursing process. For this project the following will be applied:

- Assessment: communicating with the patient to gather data, including patient history, gaps in patient understanding of disease process, and information about baseline knowledge of advance directives
- Diagnosis: analyzing the gathered data including patient concerns and identifying barriers to completion of advance directives; which includes an assessment of literacy
- Planning: developing a plan with the patient that includes his or her goals as related to advance care planning and the surrogate that would be most apt to advocate for and honor the patient and his or her values, goals, and preferences
- Implementation: putting interventions in place to increase patient knowledge while increasing the rate of completion of advance directives
- Evaluation: reviewing the rate of completion of advance directives and to assist the patient over time, as the illness progresses and goals of care change

Advance care planning (ACP) helps patients prepare for current and future decisions about medical treatment. ACP is a continual process in which a patient's current condition and prognosis are reviewed, preferences are elicited, medical dilemmas are presented and options are discussed. The process should occur longitudinally within the context of an existing and continuing medical relationship.

System Change

Methodology and Project Design

Based on the findings from the literature review and the needs of patients with COPD in the primary care setting, the project will focus on developing and implementing an educational program that will be utilized at patient encounters within a primary care clinic. The education provided will be based upon the patient's understanding of illness (illness perception using COPD Questionnaire) followed by education related to the importance and benefit of having advance directives in place with a copy in the patient's electronic medical record.

- Identify all patients in the clinic with a primary diagnosis of COPD, using query
 documentation provided by the office manager. Principal investigator will then
 perform a chart review of these patients to determine if advance care planning has
 occurred and if conversation is documented in EMR.
- Three weeks prior to scheduled appointment, clinic support staff will mail the patient
 a cover letter explaining the proposed education, along with the Understanding COPD
 Questionnaire.
- 3. Principal investigator will phone patient within 1 week of receiving the mailer. Using the Understanding COPD Questionnaire, principal investigator will assess the patient's understanding of disease process, and increase the patient's understanding of disease management, to facilitate an effective goals of care discussion. Principal investigator will then assess patient's understanding of "goals of care". Clinic support staff will then mail the patient a copy of the Your Conversation Starter Kit. Within one week of patient receiving mailer, clinic support staff will schedule appointment for patient to discuss goals of care and advance directives with provider.
- 4. One week prior to appointment to discuss goals of care, principal investigator will phone the patient and assist with any questions or concerns they may have.
- 5. At the follow-up appointment, provider will complete advance directive forms with patient, and document in the EMR. Clinic support staff will scan copy of advance directive into EMR.
- 6. Principal investigator will make follow-up phone call to patient and mail posteducation questionnaire.
- 7. Principal investigator will determine if project has increased the rate of completion of advance directives in patients with COPD.

Discussion

Patients with COPD have voiced their concerns about dying and have reported they have received little information regarding diagnosis, prognosis, and end-of-life care, despite evidence

that has shown advance care planning improves outcomes for patients (Janssen et al. 2011). According to Janssen et al. (2011) patients with completed advance directives, who later died, were less likely to receive life sustaining treatment at the end of life, their family members reported fewer concerns with physician communication, and they felt better prepared for their loved one's death. Patients who have discussed end-of-life care with their provider did not report an increase in anxiety or depression scores; they reported an increase in their quality of life (Janssen et al. 2011).

Conclusion

In 2016, using a multicenter open-label randomized controlled trial with preference arm, Sinclair et al. (2016) studied the effect of nurse-led advance care planning with patients who had been diagnosed with advanced lung disease. Participants met with a nurse facilitator to first discuss what they understood about their illness. Janssen et al. (2011) reported many patients with COPD are not aware that they have a life-limiting illness. The preference arm of the study enabled participants with strong preferences to be assigned to their preferred group (to either receive or decline intervention). Sinclair et al. (2016) did demonstrate that systemic screening to identify patients with advanced lung disease was acceptable to clinicians and participants, and that nurse-led advance care planning discussion did lead to an uptake in advance care planning. Evidence has shown that advance care planning improves outcomes for patients and their families and further supports the use of advance directives to offer direction and guidance to clinicians involved in their care (Janssen et al. 2011). Patient-clinician conversations concerning prognosis and preferences for life-sustaining treatment must occur prior to emergent hospitalization for respiratory failure.