COPD for Life

A White Paper

American Lung Association®
COPD for Life

Contents

Executive Summary

Chronic obstructive pulmonary disease (COPD), which includes chronic bronchitis and emphysema, is a life-long lung disease caused by airway damage resulting in airflow limitation, making it hard to breathe. Despite being treatable and often preventable, COPD is a leading cause of death and disability in the United States. According to data from the National Safety Council, it is the 6th leading cause of death in the United States. Based on information from 2023, approximately 11.1 million adults in the United States are living with COPD.

There has been significant progress in the care and treatment options available for managing COPD in the past decade. Individuals both newly diagnosed and those who have been living with the disease for years may not understand, have access to, or be aware of the treatment options available to them or tools that can assist in having an improved quality of life while living with a chronic lung disease. Access and understanding of the resources available to improve disease self-management skills are key to individuals having improved health outcomes.

Research shows that education is a proven method for improving patients' ability to better manage their COPD; however, barriers exist that limit access and understanding of treatment options and supportive services for those living with COPD. Obstacles to managing one's COPD include access to the resources and understanding of these resources. The American Lung Association aimed to build on this knowledge by expanding the understanding of where the gaps exist in better self-management of COPD through an extensive literature review, improved understanding of the lived experience by listening to those who have been living with COPD for ten or more years, and by partnering with other national organizations to ensure a comprehensive approach was incorporated into these efforts.

The information garnered through the efforts to better understand the gaps existing for optimal disease management provided the framework for the development and dissemination of the educational materials created for this program. These findings along with the involvement of the many stakeholders impacted by COPD resulted in a comprehensively informed educational campaign.

Background

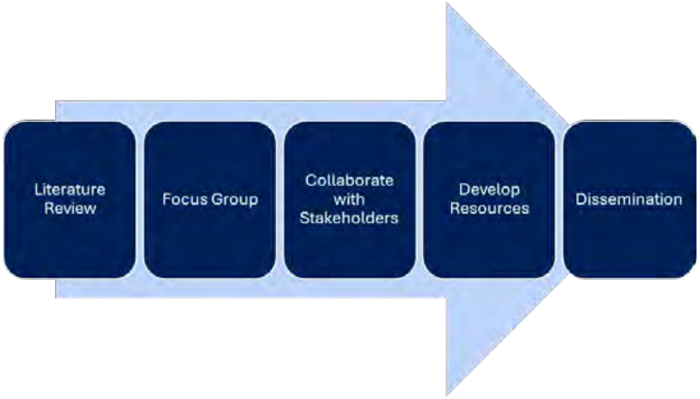
In late 2022, the American Lung Association, with support from Sanofi and Regeneron, embarked on a health education program, *COPD for Life*, aimed at raising awareness about the current guidelines for COPD management and improving accessibility of resources with a goal of improving the self-management skills of those living with COPD for better health outcomes and quality of life. The primary audience for this program was individuals living with COPD for ten or more years and communities that are disproportionately impacted by COPD including women, individuals living in rural areas and people living below the federal poverty threshold, as well as the caregivers of those living with COPD.

COPD results in a significant burden for those living with this chronic lung disease and their communities. In 2020 more than 335,000 people, about half the population of Wyoming, were hospitalized due to their COPD and there were 925,000 COPD emergency department visits that same year. The medical cost of COPD is $24 billion each year among adults 45 years of age and older including $11.9 billion in prescription drug costs, $6.3 billion in inpatient costs, $2.4 billion in office-based costs, $1.6 billion in home health costs, $900 million in emergency department costs and $800 million in outpatient costs.

The personal burden of living with a chronic lung disease goes beyond the cost of the disease to the daily impact. Insightful feedback provided by individuals living with COPD regarding the day-to-day impact of this disease on themselves as well as their caregivers included some of the following comments.

- “I tire out a lot easier than I used to. I find that when I plan my day, I try to plan it for the mornings because I know by afternoon I’m done. I can’t get anything substantial done.”
- “I was just thinking the other day. If I were ever to have to go to prison, I’d probably do well in solitary confinement because that’s pretty much how my life is now.”
- “My support system is my husband who had to go from husband to caregiver and it was a big adjustment.”

There is hope for those living with COPD and their support persons. Although there is no cure for COPD, it can be managed with a variety of treatment interventions, ranging from medications, good nutrition, incorporating the right amount of physical activity to having a good support team in place. However, barriers exist to ensuring that these interventions are implemented into everyone’s self-management regime. The methods utilized in this project aimed to better understand these obstacles and to utilize this knowledge to inform the development and dissemination of the resources created.



Methods

The methods employed to inform this educational program included completion of a literature review, engagement of a focus group, collaboration with stakeholders impacted by this disease, development of resources that integrate the findings from these activities, and formal evaluation of the program tasks and assets.

I. Literature Review

The American Lung Association researched peer-reviewed journal articles related to COPD, the role of education in disease management, health literacy, the impact of supportive services in disease management, and groups that are disproportionately impacted by COPD. This review found that patient education can improve COPD self-management, provide skills for coping with anxiety and other mental health challenges, and improve overall health status, especially as measured by quality of life and increased ability to participate in everyday activities. In addition, research shows that education and support for people living with COPD can be instrumental in decreasing exacerbations and hospital admissions. Research also shows that it is critical to develop resources that are easy for everyone to understand.

a. Summary of Findings

Education and delivery of care, both at the onset of a disease diagnosis as well as ongoing throughout the chronic disease process, and the ability to adequately access and utilize the information is a core component to improved health outcomes. Education is crucial to self-management of COPD and has been shown to improve health outcomes and patients' quality of life. Key areas that are important for individuals living with COPD to understand when managing their disease include monitoring their symptoms, following an action plan, having coping strategies in place to manage stressors that accompany having this chronic disease, and adherence to their treatment regime and lifestyle choices. Research has shown that knowledge gaps exist for patients living with moderate to severe COPD and their support persons and that they would benefit from education related to their disease and their general health throughout the disease process.

Health literacy is a significant issue in the United States and impacts patients' ability to properly manage their chronic lung disease. Health literacy encompasses having access to, understanding, and being able to apply information to make well informed decisions about your health. Access to resources, whether they are in a format that is at too high of a reading grade level, in the wrong language, or only available in digital format, is instrumental to health literacy being a contributing factor to proper education and adequate delivery of care options. The ability to understand educational resources related to health management and to have equal access to these resources disproportionately impacts certain groups.

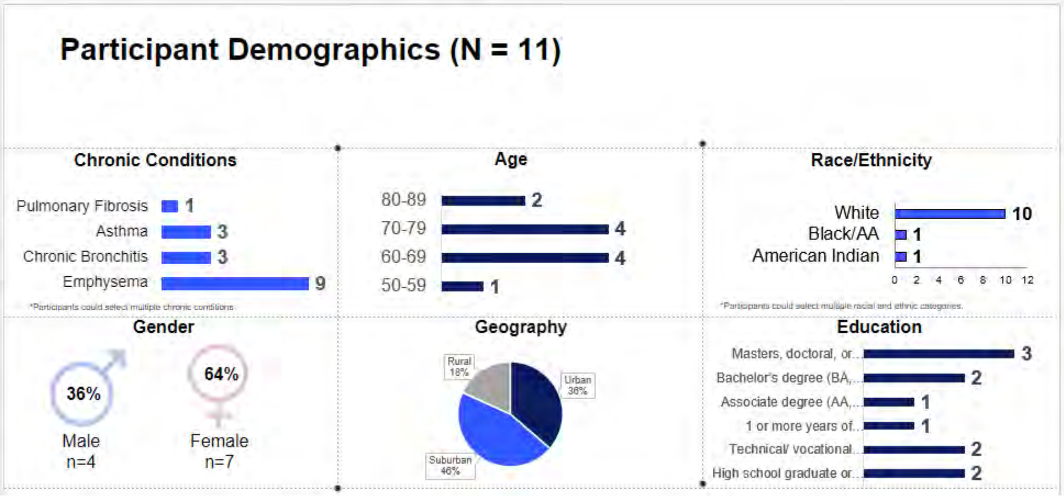
A further gap in optimal self-management of COPD occurs in access to support options, including support groups specific to living with a chronic disease. Social support is associated with improved health outcomes, noted to result in improved health choices and provides educational opportunities for better disease self-management. There are a number of groups that are disproportionately impacted by COPD and their ability to manage their disease, including women, those with a lower socioeconomic status, and individuals living in rural communities. These groups all experience limited access to resources in some form that results in an increased burden of disease for them.

See Appendix A: Literature Review.

II. Focus Group

In January 2024, the American Lung Association conducted three focus groups to better understand the qualitative experience of those living with chronic obstructive pulmonary disease for ten or more years. The goal of the focus groups was to learn about the lived experience, taking a more in-depth look at the participants' feelings, opinions, and needs as related to their quality of life and disease management.

Eleven individuals participated in the 90-minute focus groups held virtually and moderated by a professional third-party facilitator. The topics discussed during the sessions included quality of life while living with a chronic lung disease, symptoms, treatment history and ongoing disease management, healthcare team communication, education, caregiver involvement and overall care. Several themes emerged during these sessions highlighting the impact of living with a chronic disease both on the individuals as well as their significant others.



Four main themes emerged from the feedback from the participants. The first was that COPD is a life changing diagnosis impacting the intricacies of all daily living skills, from basic activities of daily living to instrumental activities of daily living. Second was the realization that disease management goes beyond medication, including the need for lifestyle changes and ongoing education. The third theme was that there are barriers to optimal disease management. Participants identified these as lack of access to services, lack of communication and information sharing among healthcare providers, lack of education from healthcare providers, and the feeling that new treatment options do not exist. Focus group members identified that they would like more time for consultation with their providers and more information on symptom management than is typically provided with intermittent appointments and limited face time, especially with specialists. The fourth theme identified was the emotional impact this chronic lung disease has on the lives of those living with COPD and their caregivers.

> *"I do sort of feel like* **it's down to me to figure it out and put the pieces together.** *Doctors don't really give you a lot of information."- Focus Group Member insight*

See Appendix B: Focus Group.

III. Collaborate with Stakeholders

An essential component of this program was ensuring effective collaboration between internal and external stakeholders impacted by COPD. The stakeholders involved in this effort were numerous. There was a coordinated effort to ensure that all stakeholder voices were heard, and impactful feedback was incorporated into the development and dissemination of the resources. Stakeholder involvement throughout the process allowed for a deeper understanding of the needs of all individuals impacted, ensured alignment of priorities, and led to a more effective and impactful campaign.

IV. Development and Implementation of Resources

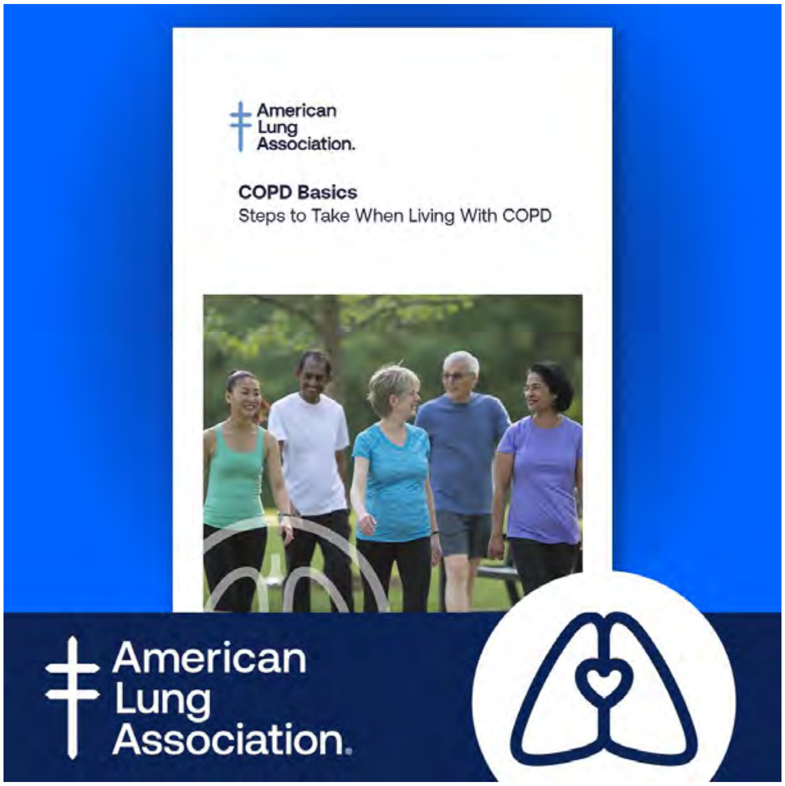
The development of this program's resources was informed by the literature review and focus groups' findings. The following resources were developed or implemented to address the goals of this project.

a. COPD Action Plan

The American Lung Association has long had a comprehensive COPD Action Plan, in English and Spanish, available to download for free on its website. This worksheet lists the steps to take to manage your COPD depending on how you feel and provides information on how to prevent COPD exacerbations. The original Action Plan remains available, but a new version was developed to incorporate best practices for health literacy. It was developed with input from external partners and went through a formal evaluation process from the Public Health Management Corporation (PHMC), as well as a review by a patient advisory group. This COPD Action Plan is available free on the Lung Association website in English, Spanish, Tagalog, and Simple Chinese.

b. COPD Basics Booklet

The Lung Association offers a COPD Basics online learning module. This is a self-paced educational module that is ideal for people diagnosed with COPD and their support persons. The content from this online educational module was transformed into a free and downloadable booklet for this program. The booklet was developed to ensure integration of health literacy best practices and for improved accessibility of the material by having this resource in a hard-copy format for those with limited or no online access. Educational information related to understanding COPD and how to best manage the disease is presented at a 5th grade reading level, in a teach-back method with guidance on when to reach out to one's healthcare provider to ensure the best plan for self-management of the disease is in place. The revised COPD Action Plan is included in the COPD Basics Booklet. The booklet is currently available in English at no cost on the Lung Association website and has been translated into Spanish and will be available soon, also at no cost, on the website.



American
Lung
Association.

COPD Basics
Steps to Take When Living With COPD

American
Lung
Association.

c. Lung Health Navigator Program

A Lung Health Navigator program was launched through the Lung Association's National HelpLine as part of the resources aimed at improving accessibility of disease management tools. The Navigators are available via telephone or online to offer this free service, including a series of one-on-one sessions. The Navigators provide education for improved self-management, skills for coping with the mental health issues associated with living with a chronic lung disease and empower people to make lifestyle changes to effectively manage their lung disease. The Lung Health Navigator program provides individuals and their caregivers with trusted, accessible, evidence-based and accurate information and programs to help manage their lung health with a goal of improved health outcomes. Lung Health Navigators fill a gap for individuals living with COPD that do not have services in their community or are unable to access those services due financial, health, or other disadvantages. Educational sessions are enhanced with materials mailed out to the participating individuals to ensure they have access to a COPD Action Plan and educational tools.

Meet Tiffany, one of our dedicated COPD Lung Health Navigators!

"I love the opportunity to meet clients where they are and give them the tools they need to better manage their lung disease."

- Tiffany

d. Ask the Expert

An *Ask the Expert* discussion was held for one-week on the peer-to-peer online support platform, Inspire. During this week-long event, community members from across the country were able to ask a lung health expert questions related to treatment and management options for COPD. The guest expert, a pulmonologist and critical care physician, answered questions over the course of the week and the session remains live on the platform for ongoing learning opportunities for the Inspire community. This platform allows for broader reach with availability to individuals regardless of geographic location.

e. Storyteller Blog

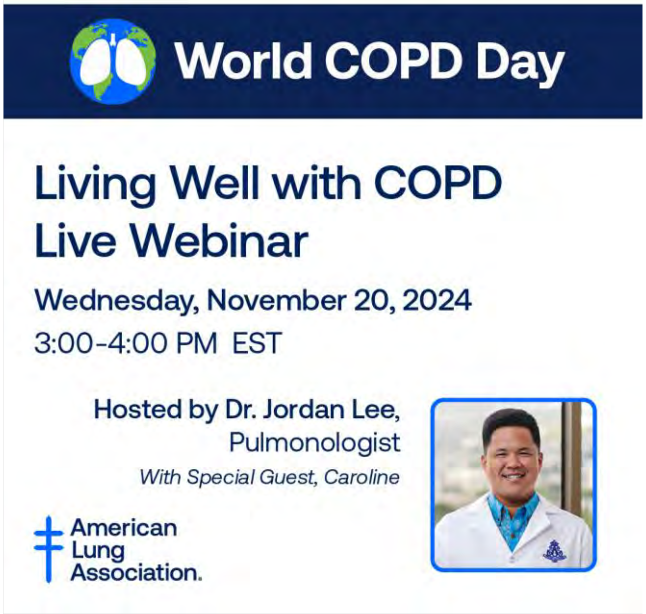
A patient living with COPD for over twenty years shared his story for an online blog article on the Lung Association website. His personal narrative provided a relatable experience to engage the audience and communicate the intended health message. The blog focused on the importance of managing COPD throughout all stages of the journey and steps that individuals living with COPD can take to improve their quality of life. This platform is widely accessible and provides a broad reach to promote behavior change.

f. Myths About COPD Article

News content highlighting common COPD myths that may impede individuals from living their best lives while living with this chronic disease provided actionable guidance on how to improve health outcomes. The article was released nationally in English, Spanish and through a radio announcement.

g. Webinar

A national, free live webinar was held to provide information on Living Well with COPD with up-to-date treatment and management options provided by a pulmonologist and critical care physician. A patient storyteller shared her journey with COPD to provide a relatable message to participants regarding real-life implementation of evidence-based recommended disease management strategies.



World COPD Day

Living Well with COPD
Live Webinar

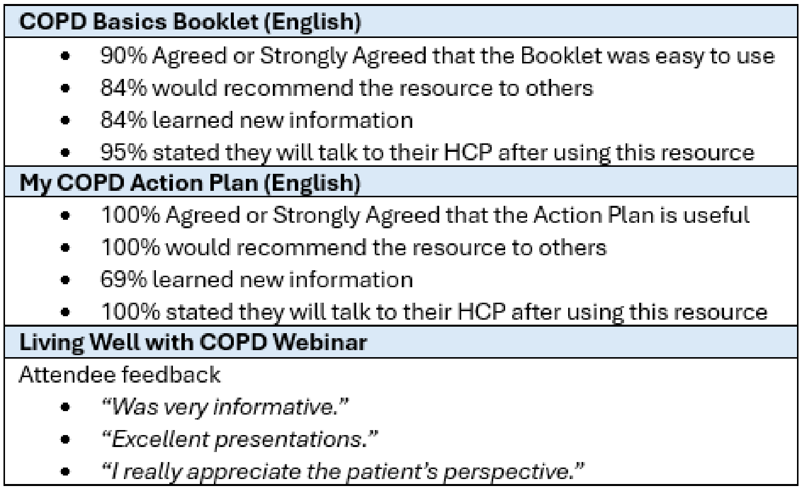
Wednesday, November 20, 2024
3:00-4:00 PM EST

Hosted by Dr. Jordan Lee,
Pulmonologist
With Special Guest, Caroline

American Lung Association.

h. Program evaluation

Individuals using some of the resources developed for this program had an opportunity to complete an anonymous survey conducted by the Research & Evaluation Group at Public Health Management Corporation (PHMC). The purpose of these surveys was to gather data on how well the resources are being received and understood by the target audience, allowing for necessary adjustments and improvements to be made based on user feedback on the overall effectiveness, accessibility, and relevance to their needs. A full report for the surveys will be provided in CY 2025. Initial survey results/feedback are provided in the table below.



COPD Basics Booklet (English)

- 90% Agreed or Strongly Agreed that the Booklet was easy to use
- 84% would recommend the resource to others
- 84% learned new information
- 95% stated they will talk to their HCP after using this resource

My COPD Action Plan (English)

- 100% Agreed or Strongly Agreed that the Action Plan is useful
- 100% would recommend the resource to others
- 69% learned new information
- 100% stated they will talk to their HCP after using this resource

Living Well with COPD Webinar

Attendee feedback

- *"Was very informative."*
- *"Excellent presentations."*
- *"I really appreciate the patient's perspective."*

Final Assets

The research findings influenced the development of the following assets and the comprehensive digital campaign that accompanied this project which involved paid and organic social media and advertisements in targeted publications.

COPD Action Plan

The health literate Action Plan is available in the following four languages:

- My COPD Action Plan - English
- My COPD Action Plan - Spanish
- My COPD Action Plan - Chinese
- My COPD Action Plan - Tagalog

COPD Basics Booklet

- COPD Basics Booklet - English
- Will be available in Spanish in 2025

Lung Health Navigator Program

Living Well with COPD Webinar

Conclusion

Over 11 million people are living with COPD and millions more are impacted by this chronic lung disease. There is a significant need for health literate resources and increased accessibility of educational tools to assist with disease management. This campaign focused on providing critical resources that meet the needs of those impacted by COPD to help educate and provide management tools with an aim of improving quality of life. Stakeholder feedback was crucial, ensuring that the educational materials effectively met the needs of those living with COPD and their support persons. The initiative resulted in the development and dissemination of numerous educational tools to address the needs that were identified. Key learnings from this campaign will inform future campaigns.

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Appendix A
COPD for Life Literature Review

Literature Review

The Impact of Gaps in Education and Care Delivery for Individuals Living with Chronic Disease

With Focus on Accessibility

Abstract

Chronic obstructive pulmonary disease, or COPD, is a chronic lung condition with no known cure; however, there are treatment options available to help manage this disease. Long-term treatment, including pharmacological intervention, exercise, education, support, and other modalities has been demonstrated to improve the quality of life of those living with COPD (1). Improved health outcomes and quality of life for those living with COPD are impacted by various factors. The primary objective of this review is to identify what gaps exist in education and delivery of care for individuals living with chronic diseases, especially COPD, which impacts optimal quality of life. This review also aims to determine which groups may be disproportionately impacted by the gaps that exist. The information gained from this review is intended to be used to increase the understanding of what these gaps are and to use this knowledge to inform the development and dissemination of educational resources available to individuals living with COPD and their support persons.

The Role of Education in Disease Management

Education is crucial to self-management of COPD and has been shown to improve health outcomes and patients' quality of life (2). Ongoing treatment management strategies, including pharmacological and non-pharmacological management such as education, should occur throughout the disease process for optimal symptom management and reduction of exacerbations (3). Key areas that are important for individuals living with COPD to understand when managing their disease include monitoring their symptoms, following an action plan, having coping strategies in place to manage stressors that accompany having this chronic disease, and adherence to their treatment regime and lifestyle choices (4). Research has shown that knowledge gaps exist for patients living with moderate to severe COPD and their support persons and that they would benefit from education related to their disease and their general health (5).

Health Literacy

Health literacy is a critical component impacting a person's ability to self-manage their chronic disease. It refers to the ability of a person to have access or find information, understand, and apply this information to make well-informed decisions to manage their health (6). People with lower health literacy skills are more likely to have difficulty managing a chronic disease and have poorer health outcomes (7). Approximately one in three adults in America lack basic numeracy skills and 35% have lower than intermediate health literacy skills (8, 9). The Centers for Disease Control and Prevention (CDC) found that people that are well read also may have health literacy issues for several reasons including unfamiliarity with medical terms, needing to interpret statistics, being impacted by the emotional component of having a serious illness, and having health conditions that require complex care (10). A study conducted by Burns, Amobi et al (2016) found that the majority of instructional discharge information (>88%) written for patients was consistently at a level higher than the recommended sixth grade reading level, making these patient-facing materials inaccessible (11). Studies have also shown that many patients are confused about their health care plan after being discharged from the hospital and that a significant amount of information that they are given prior to discharge is either unable to be recalled or is remembered incorrectly (12). Access to educational information may also be influenced by limitations in digital health literacy which involves an inability to access health information available electronically or web-based due to lack of means or ability (13). One study found that the average reading grade-level content related to medical content found electronically or web-based is frequently higher than a 10th grade reading level with the National Institutes of Health (NIH) coming in at a 10.7 grade-level and the Mayo Clinic at an 11.3 grade-level (14). Individuals impacted by social determinants of health and certain demographic groups may be disproportionately affected by digital health literacy (13).

The Role of Support

Social support in the context of one's health, includes the availability of psychological and material resources by a social network, informal or formal, that aims at improving the person's ability to manage their disease (13). People who have social support are more likely to make healthier choices and have better health outcomes, such as reduced anxiety or depression (15). Studies indicate that patients living with COPD with access to positive social support are more prone to reduced hospitalizations, fewer exacerbations, better health status, and improved disease management behaviors (16). Social connection with others is also associated with preventing death from chronic diseases such as COPD (15). Support groups for people with lung disease have shown improved self-management skills through education provided during meetings and better understanding of one's disease as a result of participating in the group (16). Lack of social support is a barrier to optimal self-management of a chronic disease (16). Russell, Ogunbayo, et al, found that healthcare providers may not have enough time, resources, or the adequate skills to address their patients' psychosocial needs, thus limiting access to these services through omission (17). As a result, individuals living with COPD may not be offered or aware of the beneficial role of supportive services in improving quality of life and health outcomes.

Groups Impacted

There are certain groups of people that are disproportionately affected in the management of their COPD. Groups experiencing disproportionate impact include women, people of lower socioeconomic status, older adults, and those living in rural areas (18). Women frequently have a delayed diagnosis, a significant impact on their quality of life, and more difficulty with breathlessness, anxiety and depression related to their COPD (19). How the disease is managed in women needs to be further scrutinized to ensure that they are getting timely and appropriate access to care, and the necessary and ongoing education related to their disease. Lower socioeconomic status has been shown to negatively impact quality of life, severity and mortality related to COPD (20). Studies have found lower socioeconomic status has been linked to disproportionate access to health care in many diseases (20). Finally, COPD prevalence is higher in rural communities and there are more exacerbations that lead to hospitalizations in rural areas (21). Rural residents have higher poverty rates and are more likely to be uninsured. Both of these are contributors to having less access to timely diagnosis and treatment (21).

Conclusion

Education and delivery of care, both at the onset of a disease diagnosis as well as ongoing throughout the chronic disease process, and the ability to adequately access and utilize the information is a core component to improved health outcomes. Health literacy is a significant issue in the United States and impacts patients' ability to properly manage their chronic lung disease. Health literacy encompasses having access to, understanding, and being able to apply the information to make well informed decisions about your health. Access to resources, whether they are in a format that is at too high of a reading grade level, in the wrong language, or only available in digital format, is instrumental to health literacy being a contributing factor to proper education and adequate delivery of care options. The ability to understand educational resources related to health management and to have equal access to these resources disproportionately impacts certain groups. A further gap in optimal self-management of COPD occurs in access to support options, including support groups specific to living with a chronic disease. Social support is associated with improved health outcomes, noted to result in improved health choices and provides educational opportunities for better disease self-management. There are a number of groups that are disproportionately impacted by COPD and their ability to manage their disease, including women, those with a lower socioeconomic status, and individuals living in rural communities. These groups all experience limited access to resources in some form that results in an increased burden of disease for them.

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Appendix B

Focus Group Blog, What’s it Like Living with COPD?