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Chronic Obstructive Pulmonary Disease and Social Determinants of Health

A Case of Marginalization in Rural Appalachia

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Chronic obstructive pulmonary disease remains a challenging epidemic across the United States. This serious illness impacts nearly twice as many individuals in the rural area compared with urban counterparts. As the disease progresses, the symptom burden and needs of the patient and caregivers escalate. Access gaps to services, such as hospice and palliative care, and the social determinants of health found in Appalachia may lead to marginalization and social injustice. Defined as the condition of being peripheralized based upon one's social margins of identity, associations, and/or environment, marginalization impacts health outcomes and quality of life. This article explores the triple threat of marginalization for patients with chronic obstructive pulmonary disease living in rural Appalachia. By recognizing marginalization and designing initiatives to reduce the impact, hospice and palliative care nurses serve as advocates and leaders to influence systemic change through partnerships with key policymakers and legislators.

KEY WORDS

Appalachia, chronic obstructive pulmonary disease (COPD), hospice care, marginalization, palliative care, rural health, social determinants of health

Chronic obstructive pulmonary disease (COPD) is the leading cause of morbidity and mortality worldwide with an estimated 328 million cases and 3.23 million deaths as of 2019.[1,2] Chronic obstructive pulmonary disease will likely be the leading cause of death worldwide in 15 years.[3] In the United States, more than 15 million people experience COPD with approximately 150000 deaths annually.[4] The COPD economic impact is staggering. According to the Centers for Disease Control and Prevention, the 2010 direct costs of COPD totaled $32.1 billion and the indirect costs (ie, unpaid caregivers) were $20.4 billion.[5,6] The actual costs associated with COPD since 2010 have yet to be reported. Ultimately, the burden on the national health services continues to increase exponentially.

Even more troublesome is the incidence of COPD in rural communities where it is nearly double that of urban counterparts (8.2% vs 4.7%).[7] In Appalachia, the mortality rate is higher than that in the United States (53.5 per 100000 population vs 42.0 per 100000).[8] Meanwhile, age-adjusted death rates are increasing in rural areas compared with a decrease in urban settings.[8] The Appalachian regions are especially vulnerable where approximately 20% of adults reportedly smoke compared with 16% of adults in non-Appalachian regions.[8] In Central and North Central Appalachia, rates of smokers are considerably higher (39.3%).[9] Furthermore, these communities have exposures to organic toxic dust from farming and handling of livestock, and use of biomass fuels leading to poor air quality and pulmonary illnesses.[10,11] In addition, the aging population in these rural communities has comorbid conditions, has poor reading and health literacy, and frequently lack health insurance, all factors contributing to social determinants of health (SDH).[12]

The Appalachian landscape, with the rough terrain of steep sloping ridges, forests, and valleys, leads to geographic isolation. The geography leads to access gaps in health care services for primary and specialty care. According to the Appalachian Regional Commission, the number of primary care providers in Appalachia is 26% lower than the national average.[12] Access to specialty providers is severely limited, with some evidence suggesting only 1 pulmonologist is available within a 10-mile radius for 34.5% of rural areas compared with 97.5% in urbanized areas.[13] In the economically distressed counties in Appalachia, defined as the lowest per-capita income of the nation's counties, the supply of specialty providers is nearly 76% less than those in nondistressed counties.[12] With isolated clustered communities of 26 million people across 13 states and 423 counties,[8] this region experiences marginalization.

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Unhealthy behaviors and lifestyle choices coupled with environmental exposures and lack of primary and specialty providers to care for these patients lead to increased comorbidities and premature death. These characteristics of Appalachia, such as isolation, economic hardships, and health behaviors, frequently lead to marginalization.

Hall et al[14] (1994) proposed the concept of marginalization as a means for the nursing profession to address vulnerable populations. Marginalization, the condition of being peripheralized based upon one's social margins of identity, associations, and environment, impacts health outcomes. These margins create an individual's social and/or psychological isolation, which adversely impacts physical and emotional health and intensifies both the perceived and objective distance to resources.[15] Factors such as serious illness, geographic location, and SDH contribute to marginalization. For example, COPD is typically associated with smokers, a more prevalent unhealthy behavior in rural communities as compared with urban settings.[10] However, in Appalachia, farmers, coal miners, and mill workers also have environmental exposures that contribute to the development of COPD.

This article illustrates the link between patients with COPD in rural Appalachia with marginalization and its associated subconcepts of intermediacy, differentiation, power, secrecy, reflectiveness, voice, and liminality. The population of patients with COPD and their caregivers living in rural Appalachia experience a triple threat for marginalization by (1) disease, (2) geography, and (3) SDH (Figure).

CASE STUDY

Mrs Alexander, aged 76 years, has lived in Crab Orchard, Tennessee, for her entire life. This region is part of the

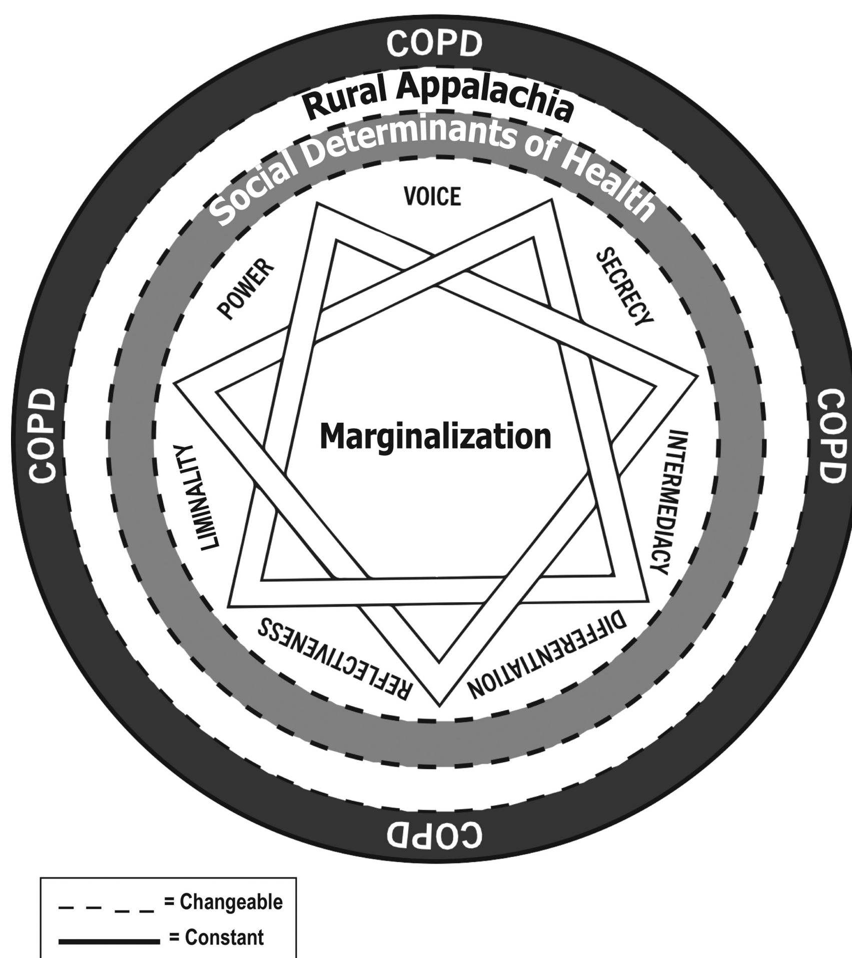

FIGURE. The Triple Threat for Marginalization model illustrates the relationship between marginalization and patients with chronic obstructive pulmonary disease (COPD), rural Appalachia, and the social determinants of health. Each subconcept provides a foundation for greater understanding of marginalization. Individuals may be able to change their geographics and social determinants of health, but a diagnosis of COPD is constant. These individuals present unique challenges to hospice and palliative care providers.

rugged range of the southern Cumberland Mountains. The town has less than a thousand people, 2 stop lights, 2 gas stations, and a general store. She lives in the old family home heated by coal and has a 30-year history of working in a cotton mill. She does not share much about her husband except to say he is around. Her son and daughter-in-law live nearby and have been adamant about her moving in with them. However, she is fiercely independent and feels she can take care of herself, even when her breathing becomes labored. Mrs Alexander was given a diagnosis of COPD nearly 12 years ago by her primary care doctor. She is a smoker and does not leave the house often because she does not want her friends to know that she still smokes. She does not believe she has COPD and rarely uses the recommended oxygen therapy. When she does, she says, “People just stare at me. I don't like it. I'm NOT going to wear it. I don't want to become dependent on oxygen.” She tried to get a portable oxygen concentrator, but the monthly rental fee was too much, even with her insurance coverage. She only uses her pulmonary inhalers as needed instead of as prescribed because of the cost of the medication. She has not reported this to her provider.

MARGINALIZATION SUBCONCEPTS

In the last several years, there has been an explosion of media coverage related to marginalized groups and individuals. Yet, if you ask, “What does it mean to be marginalized?” many have difficulty defining the term and truly grasping the full meaning of the concept within the context of health care. Examining the 7 subconcepts, as proposed by Hall et al[14] (1994), provides a greater understanding of marginalization and its impact on vulnerable populations such as those living with COPD. In this article, each subconcept will be explored in the context of patients with advanced COPD, rural Appalachia, and the SDH.

Intermediacy, a core principle of marginality, refers to the boundaries that act as both barriers and connections in one's life.[14] An individual uses these boundaries for self-worth, preservation, and maintaining autonomy. Microenvironmental and macroenvironmental factors shape these boundaries. For example, Mrs Alexander might experience microlevel barriers by isolating herself during an exacerbation or at the end of life to preserve respiratory function and autonomy. Conversely, a macrolevel connection might include seeking out palliative care or hospice services to help alleviate breathlessness, anxiety, and feelings of helplessness. Ultimately though, the boundary barriers of intermediacy are intensified in Appalachia because of decreased access to care and limited resources. The triple threat invades the overall well-being of the patient and his/her caregiver.

Differentiation builds upon intermediacy by preserving self through strengthening and maintaining an individual's unique identity.[14] With differentiation, the individual works to maintain self-identification, at the same time placing boundaries to prevent others from influencing their view of self. Social norms and appearances at society's core reflect uniformity and independence, typical of healthy individuals. Individuals with COPD, such as Mrs Alexander, frequently lose their identity as the illness progresses, requiring greater dependency on caregivers and health care systems. They experience physical changes, such as muscle wasting, barrel chest, and ecchymosis. Medications for symptom management, such as opioids and benzodiazepines, further differentiate the patient from society's core image of healthy individuals. Geographically, individuals in rural Appalachia are more insulated because of the mountainous terrain and weather conditions of snow, ice, and/or flooding. Given these conditions, access to care is more difficult for the patient and caregiver especially as they become more dependent on health care services.

Power entails influence that flows from the center outward and the margins inward.[14] Although this power remains bidirectional, there is a hierarchical structure in which the decision-making core dictates to the margins and power dissipates as it flows outward. Success of the hierarchy relies on the invisibility of those individuals at the margins. In the case of Mrs Alexander, as the symptoms progress, power rests more with her provider and family. She values independence and self-reliance, but the hierarchical structure is dictating otherwise. Individuals with advanced COPD consistently face power struggles, particularly those who continue to smoke, given societal views on smoking and failure to quit. Smokers are well aware of the health impact of tobacco use, such as developing COPD, but experience marginalization as a result of their choices. In addition, the Appalachian region is particularly vulnerable to loss of power given the proliferation of coal and timber industries consuming natural resources, leaving communities with poor air quality.[16] More recently, the demand for coal has declined and with that, employment opportunities and increased poverty. Associated heavy losses in revenue and employment further distress the SDH and accelerate marginalization.[17]

Secrecy relates to withholding information to be viewed as possessing similar characteristics to those at society's core.[14] Individuals with COPD experience significant pressure from society and tend to hide, even disguise, their illness and symptoms. They conceal their diagnosis for fear of being judged, which also leads to avoidance of medical attention. Within a group setting, they use various strategies to obscure their suffering.[18] For example, Mrs Alexander allows her friends and family to walk ahead of her up a flight of stairs to conceal her shortness of breath and fatigue. When asked about her current and past smoking use, she hides the truth because of the lack of trust and fear of retribution. The use of secrecy provides a safety net to maintain a semblance of power, ensure self-protection, and avoid betrayal.

Appalachian communities are tight-knit, very private, and typically suspicious of outsiders.[19] They keep to themselves to protect "self" and maintain independence, which ensures a power position. Even with limited financial, health, and employment opportunities, they avoid disclosure of the impact of these limitations to maintain a perception of power. An individual given a diagnosis of COPD coupled with residing in an Appalachian community exemplifies the definition of secrecy, an element of marginalization.

Reflectiveness is the process of rumination, thereby examining and reexamining to understand lived experiences.[14] As an outcome of lived experiences in the margins of society, the individual may realize how differentiation, the use of secrecy, and loss of power have impacted him/her. Those individuals with COPD reflect on past exposures, such as smoking, coal mining, or working in textile mills. As the symptoms worsen, the rumination becomes cyclic and more intense. The smoker vividly recalls the age and circumstances in which he/she started smoking. The coal miner and textile worker reflect on their limited employment options in rural Appalachia. Many were forced into these positions to support their family, despite the associated hidden adverse health consequences. To date, coal mining remains the highest paying job in the region, whereas most textile mills have disappeared. Additional employment opportunities, such as those found in Appalachian extractive industries (those companies harvesting resources from underneath the earth) and biomass companies (harvesting Appalachian forests), further contribute to pollution of air, water, and soil.[20]

Voice is an essential element of power for the decision-making center secondary to its collective nature.[14] The inability to express oneself, or fully comprehend verbal and written language, using the semantics of the decision-making core leads to marginalization. The marginalized voice can range from diminished to completely absent contributing to an individual's lack of power. Sadly, many COPD patients self-silence, like Mrs Alexander, failing to ask questions or share their symptom burden with providers. These patients struggle to understand complicated medical terms and truly express their physical limitations. In addition, low reading and health literacy impacts the full comprehension of symptom management strategies, such as the benefits of inhalers, oxygen, and opioids.[21] These literacy issues contribute to poor quality of life and adverse health outcomes.[22] Well-intentioned providers may inadvertently silence patients with their use of medical jargon far above what the patient and caregivers understand. The provider's nonverbal actions during the encounter, such as computer charting or multitasking, suggest disinterest in the patient-caregiver dyad's attempts to share their challenges of living with COPD.

Plagued by physical ailments, such as shortness of breath and air hunger, individuals with advanced COPD are unable to fully express their desires and wishes. As the symptoms progress and quality of life declines, caregivers and providers tend to dominate decision making, ultimately diminishing the patient's voice. With a decreasing voice in decision making, compounded by fatigue and activity intolerance, these patients frequently miss appointments. They may lack endurance to drive themselves to appointments or to travel long distances. Family or friends may offer to drive them to their appointments but may have sudden scheduling conflicts arise. As a result, many needs go unrecognized and unmet.

Many patients with advanced COPD are unable to maintain employment in the Appalachian region given the employment type is frequently manual labor created from the abundant resources of the land and forest. However, these physically demanding positions rarely match salaries equivalent to urban salaries. Patients are forced to seek employment opportunities that are sedentary, further potentiating debility. Furthermore, the ongoing economic distress in Appalachia has contributed to development of industry partnerships, such as biomass plants, which contribute to air pollution and the development and worsening of respiratory conditions.[8] Many of these partnerships, under the veil of reducing poverty and joblessness, invade rural communities already marginalized with diminished voice. The geographic landscape and SDH inherent to Appalachia add to the dilemma of the diminished or absent voice of the COPD patient and caregiver.

Liminality is a subconcept that seems more ambiguous because it deals with alteration and intensification of time perception, worldview, and self-image.[14] Marginalized individuals may display characteristics of edginess, hypersensitivity, and hyperresponsiveness to those around them. These behaviors place a strain on relationships with caregivers, family members, and health care providers. Patients with advanced COPD have an altered self-image from physical changes, such as stained fingers from smoking, weight loss, and lower extremity edema.[23] These changes are notably different from society's norms and can result in body shaming by caregivers, family members, and others. In addition, many of these patients rely on oxygen therapy and may use portable delivery modalities that are bulky, noisy, difficult to maneuver, and attract further attention to their deteriorating condition. As with Mrs Alexander, many patients opt out of the use of oxygen and experience increased symptom burden, which further contributes to their emotional hypersensitivity. The psychosocial constructs frequently seen in Appalachia, such as low socioeconomic status and poor quality of life, increase their marginalization. Their perception of time intensifies as the disease progresses, and they reflect on proposed life expectancy.

DISCUSSION

Appalachia poses several challenges for people with serious illnesses and physical disabilities. Secondary to its rugged

terrain and harsh weather, the geography of this region isolates many communities contributing to barriers in access to health care. In fact, 181 rural hospitals have closed since 2005, with 52 of these between 2018 and 2020.[24] The impact of this loss is particularly felt by the older adults, minorities, poor people, and people with disabilities. Even before the closing of these facilities, much of Appalachia had been classified as health care shortage areas.[25] It is difficult to attract health care providers, particularly specialists, to the region in the absence of acute care hospitals. When specialty care is needed for illnesses, patients must coordinate transportation to travel long distances, accumulating additional costs and time lost.

Social relationships are an important part of Appalachia, a region known for their tight-knit communities. Patients build trusting relationships with their health care providers over time but will be initially cautious and withhold information. This is especially true in cases when the provider is new to the region and unfamiliar with local culture. These communities tend to have a strong distrust of outsiders and are reluctant to accept anyone other than the locals.[26] Without a trusting relationship, the patient may withhold vital information about medical history and symptom burden. Without full disclosure of information, a comprehensive treatment plan cannot be rendered. It may take multiple visits before a patient feels a trusting connection to fully disclose information.

Mistrust of outsiders and SDH, such as poverty and access to care, contribute to delayed identification and appropriate management resulting in poor outcomes for seriously ill patients, such as those with COPD. Managing the disease and associated symptom burden can be costly. For example, pharmacological therapies such as rescue inhalers can be costly and prevent utilization.[27] Other social determinants, such as lack of education, inadequate transportation, and racial inequality, are linked to unhealthy lifestyles. With COPD, the level of education and socioeconomic status are major contributing factors to increasing mortality.[28] In Appalachia, fewer than 3 of 4 working-age individuals completed high school, which contributes to a lower socioeconomic status.[29] The marginal status of these patients contributes to adverse health outcomes because it places them at the periphery of society socially and encourages them to be invisible, powerless, and vulnerable.

NURSING IMPLICATIONS

The American Nurses Association Code of Ethics clearly articulates nurses' ethical responsibility to advocate for patients and caregivers.[30] As such, nurses should be keenly knowledgeable of marginalization and the associated subconcepts to improve their patient's health and quality of life. By recognizing marginalization and designing initiatives to reduce the impact, nurses can serve as advocates and leaders to influence the needed systemic change.

The first step in improving marginalization for patients in rural communities would be educating them and their trusted providers on community-based palliative care. By embedding trained palliative care providers into clinics and health systems, patients and caregivers would receive much needed support as they navigate the trajectory of serious illnesses and end-of-life care. Using an embedded model, rural primary care providers can evolve into palliative care champions to build and sustain the needed workforce to provide this essential care.

In the case of COPD, palliative management of symptoms is essential, particularly given the unpredictable trajectory of this disease and associated symptom burden.[31] The marginalized patient and their caregiver living in rural Appalachia face even more trauma and insurmountable challenges. The stress and burden of the disease within these isolated communities, compounded by SDH, leave patients, caregivers, and primary care providers with voids in care management and delivery. The inability to obtain needed services, such as pulmonary rehabilitation, medications, and palliative care, allows the condition to progress with increased symptom burden. The caregiver's responsibilities escalate, and the inadequacies contribute to the patient becoming even more marginalized. Nurses are critical for identifying the needs of these patients and caregivers, linking them to various community resources. As part of the holistic approach to care management, nurses seek out partnerships to extend intraprofessional collaboration, ultimately reducing marginalization. Organizations that promote awareness of health disparities and educate rural providers at the regional and national levels are key to bringing awareness of rural inequality.

FUTURE IMPLICATIONS

The face of Appalachia is changing with increases in diversity and population that will ultimately impact health care utilization. In 2017, the Appalachian population consisted of 81.4% White and 18.6% minority (9.7% Black alone, not Hispanic; 5.1% Hispanic or Latinx; 3.8% Other, not Hispanic).[32] Although African Americans remain the largest minority group in Appalachia, from 2010 to 2019, the African American population only increased by 0.7%, whereas the Latinx population had the largest minority increase (1.2%).[32] These increases have been attributed to employment availability in food processing, construction, and small business entrepreneurship.

A large portion of Appalachia is composed of individuals 65 years and older (older adults). These older adults make up 18.4% of Appalachia's population, more than 2% greater than the national average (16%).[32] These individuals typically have greater needs and use the health care system given their multiple comorbidities, such as COPD, cardiovascular disease, and diabetes. In addition to the increase in older adults, regions within Appalachia are experiencing

population growth. Whereas the upper regions of Appalachia have experienced population loss (New York, Virginia, and West Virginia), South Central and Southern Appalachia have increased. As of 2019, Southern Appalachian (parts of South Carolina, Georgia, Alabama, and Mississippi) growth exceeded national averages. Georgia and South Carolina's Appalachian areas increased by 11% with some pocket communities increasing as much as 38.3%, whereas the US population only increased by 6% from 2015 to 2019.[32]

With such an increase in population, hospice and palliative care nurses will need to focus efforts on advocacy and supporting cultural awareness to prevent further marginalization of the growing, diverse population in Appalachia. Innovative strategies, including telehealth, will be necessary to reach the most rural patients in these regions. Historically, Internet availability has been poor in this area and even absent in many Appalachian communities, but this is slowly improving.[33] Policy and legislative initiatives are ongoing to reduce the digital divide.

CONCLUSION

The growing issues of marginalization characteristic of rural Appalachia pose a significant threat to our nation's community health and well-being. For patients and caregivers living in rural Appalachia with serious illnesses such as COPD, limited resources, geographic landscape, and SDH negate opportunities to improve quality of life. Palliative and hospice nurses have firsthand knowledge of the daily challenges of patients and caregivers dealing with serious illnesses. Using the framework of marginalization and its associated subconcepts, hospice and palliative care nurses should be at the decision-making table to advocate for resources to fulfill the unmet needs of their patients and to ensure holistic care is provided for each and every person.

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DISCLOSURE STATEMENT

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