Perspective

Improving Research for COPD in Rural Areas: A Statement from the COPD Foundation Medical and Scientific Advisory Committee

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Abstract

Chronic obstructive pulmonary disease (COPD) among individuals living in rural areas is associated with worse health outcomes. New strategies are needed to study interventions and deliver proven therapies to people with COPD in rural areas. This statement from the COPD Foundation Medical and Scientific Advisory Committee highlights specific challenges in capturing the key characteristics of rural residents and identify approaches to improve research for COPD in rural areas. Specifically, geographic isolation, access to specialist care, lack of broadband access, and complex tobacco and exposure histories are drivers of COPD health disparities in rural populations that are not captured by conventional definitions of rurality. To improve the design of research studies among people with COPD living in rural settings, certain actions are identified. These include the inclusion of specific covariates such as distance and travel time to health care services and multidimensional assessment tools for societal and individual health determinants in data collection; deploying qualitative and mixed-methods research designs to assess cultural differences driving health care access and health behaviors; decentralized carousel recruitment models in study design; and operationalizing research partnerships to improve support for primary care providers engaged in research. These approaches will permit robust assessment of the complex matrices driving disparate health outcomes among people with COPD in rural areas.

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Main Text

Whether confirmed by spirometry or defined via self-report, the prevalence of chronic obstructive pulmonary disease (COPD) is higher in rural areas across all age groups and all US regions.[1] While tobacco exposure, low educational attainment, and poverty are significant risk factors for COPD, differences in COPD prevalence persist between rural and urban regions even after controlling for tobacco exposure and socioeconomic status.[2] Rural COPD patients also have increased symptoms, worse lung function, and increased exacerbations compared to urban patients.[3,4] Individuals living in non-metropolitan areas experience higher death rates from heart disease, cancer, stroke and COPD than those living in metropolitan areas. While death rates from cardiovascular disease, cancer and stroke are decreasing in both populations, COPD mortality among individuals living in non-metropolitan areas continues to *increase* while COPD mortality in metropolitan areas has stabilized.[5] These observations highlight the persistent, widening health gap between rural and non-rural people with COPD. There is an urgent need to develop new strategies to study interventions and deliver proven therapies to improve COPD outcomes among people living in rural areas. The purpose of this perspective is to highlight specific challenges in capturing the key characteristics of rural residents and identify approaches to improve research for COPD in rural areas.

The Minority Health & Health Disparities Research & Education Act of 2000 defines a health disparate population as one with significantly worse rates of disease incidence, prevalence, morbidity, mortality, or survival compared with the health status of the general population.[6] Numerous governmental agencies have operationalized rural urban classifications for population tracking, budgeting and economic research, and health related grants and research. The United States Census Bureau defines “rural” as all areas that are not “urban” (i.e., containing

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2000 housing units or at least 5000 people total per the updated 2020 Census Urban Area Criteria).[7] Similarly, the Office of Management and Budgeting (OMB) divides counties into "metropolitan area", "micropolitan area", and "non-metro/non-micropolitan area" counties.[8] Recognizing that Census Bureau and OMB definitions are often at odds with each other, the Federal Office of Rural Health Policy (FORHP) enhances the specificity of these definitions through use of Rural Urban Commuting Area (RUCA) codes and the Road Ruggedness Scale (RRS), both developed by the United States Department of Agriculture Economic Research Service (ERS).[9,10] RUCA codes delineate urban to rural classification on a 10-point scale at the census tract level by leveraging geographic, population-based and commuting data from the US Census and American Community Survey. The RRS quantifies the changes of elevation or "ruggedness" of a terrain at the census tract level to inform rural community development and wellbeing. Each of these definitions collapses the complexity of rural exposure into discrete units. A specific challenge of this approach, dubbed the Modifiable Areal Unit Problem (MAUP), is that use of various geographic units alters findings in rural health research: when a granular unit, like census block level, is used, small population changes have greater impact on statistics per geographic unit. Conversely, larger geographic units, such as counties or census tracts, may obscure heterogeneity in population distribution or health determinants faced by small, isolated communities.[11] Although there are a variety of rural-urban classification systems, a unified measure of categorization has not been agreed upon in health research, which further complicates comparisons between studies. Even when used in concert, the classifications discussed above fail to capture many of the diverse health disparities experienced in rural regions relevant to interpreting and implementing results of research studies.

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First, distance and geographic isolation matter in rural health. Expansive areas with low population density and limited public transportation make accessing thinly spread health services difficult.[12,13] For example, pulmonary specialists are limited in rural areas, with residents of rural areas traveling an average of 33.4 miles (estimated 42 minutes travel time) to the nearest site for pulmonary function tests compared with 8.4 miles (estimated 13 minutes) for urban residents.[14] Longer drive time has been associated with lower rates of guideline directed care post-discharge for COPD exacerbation.[15] Travel distance to pulmonary rehabilitation sites has also been negatively correlated with program completion.[16] Unsurprisingly, better access to pulmonary specialty care – even by as little as 1 pulmonologist for 100,000 persons – is correlated with fewer hospitalizations and emergency department visits for COPD patients.[17] As a result of decreased specialist availability, primary care providers frequently serve as the main physician managing COPD in rural regions.[14] Competing clinical priorities during primary care visits limit time available to focus on respiratory care topics, such as inhaler technique and smoking cessation counseling.[3,18,19] Furthermore, rural areas are enormously underserved by primary care physicians, placing greater reliance on advanced practice providers.[20,21] An additional challenge is that rural residents tend to seek care less frequently than their urban counterparts.[22]

Second, while telemedicine has been proposed by many, including rural primary care providers, as a stop-gap measure to intervene on rural-urban health disparities, access to the reliable broadband and cellular service necessary for telehealth interventions remains limited in most rural areas of the United States.[19,23] Efforts to implement telehealth pulmonary rehabilitation have been met with mixed success. Although some programs demonstrated clinically meaningful improvements, other web-based interventions struggled with the “digital

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divide" in internet access and the educational, economic, generational and social differences that separate rural and urban people with COPD.[24,25]

Finally, rural residents have complex tobacco and exposure histories impacting risk and progression of COPD, often not assessed rigorously in research studies. Those living in rural areas are more likely to start smoking at an early age and less likely to perceive smoking as harmful to health.[2,26] Smoking during pregnancy, more common in rural populations, also has a negative impact on fetal lung growth and birth weight, impacting COPD risk in adulthood.[27] While smoking rates across the United States have fallen, smoking rates have declined the least in populations with low socioeconomic status, notably in rural regions.[2,4,18] Environmental exposures like biomass fuel combustion may promote development of COPD among rural never-smokers.[2] Moreover, environmental exposures through occupation, such as mining or agricultural work, are greater in rural populations with low socioeconomic status and may be one reason for greater frequency and severity of exacerbations experienced by rural cohorts.[28] Understanding the impact of tobacco use and environmental exposures in rural cohorts with focused educational interventions to decrease smoking incidence is essential to mitigate the rural-urban disparity in COPD risk and progression.

From distance and geographic isolation, access to broadband, sociocultural differences that impact health behaviors and environmental exposures, it is clear there are many drivers of COPD health disparities in rural populations that are not captured by conventional definitions of rurality. Rurality as a health disparity is a heterogeneous modifier encompassing numerous domains.

Complicating our understanding of rural impact on COPD is that rural cohorts in research and clinical trials may not reflect the broader rural population. While some regions like

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Appalachia and the Midwest are largely composed of older, white residents, the Southeast, Southwest, and Northwest have seen increases in racial and ethnic diversity based on the 2020 US Census, largely attributed to rises in Hispanic and immigrant populations.[29] Conversely, perhaps the most frequently assessed rural cohort in the United States is through the Veterans Affairs administration, a population comprised mainly of older, male tobacco users.[12,24] Minority subsets of the rural population, such as Black, Hispanic, or American Indian individuals, are less likely to be included in clinical trials or rural health research, but they comprise the most vulnerable subset of the rural population with highest rates of COPD prevalence, foregone medical care, under- or uninsured status, disability, and low socioeconomic status.[3] Using a statewide telephone survey to assess the willingness of rural South Carolinians to participate in clinical trials, Kim *et al* found that rural residents were no less willing to participate in clinical research. However, they identified several structural barriers to participation, including limited accessibility, uninsured/underinsured status, and lack of public information on clinical trials. Local community physicians were frequently unaware of ongoing research trials. In addition, greater misperceptions of research and high levels of medical distrust were noted amongst minority participants and those with lower educational attainment. [30]

To improve the design of research studies among people with COPD living in rural settings, specific actions must be taken (Figure 1). Research in rural health and COPD over-relies on imprecise definitions and inconsistent geographic units. First, we must move past the term "rurality" to restructure our approach to research on disadvantaged populations in COPD. Distance and travel time are undeniable factors in patients' ability to access health care services and should be incorporated as covariates in analyses of people with COPD in rural areas. Multidimensional assessments of health determinants, such as the Area Deprivation Index or

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Research Triangle Institute rarity tool, better quantify the health disparities and life expectancy of communities and should be incorporated in COPD research.[31–34] While the rural-urban health disparity is evident, an undeniably greater racial, ethnic, and socioeconomic disparity underlies and drives these differences in health outcomes. Comprehensive tools to intentionally study *individual-level* social determinants of health should be included as exposure variables in rural COPD research settings.

Second, qualitative research studies to assess cultural differences driving health care access and health behaviors are necessary for developing health interventions that communities are able and willing to adopt. Prior qualitative research in rural access to care has demonstrated informative themes of self-reliance, passive acceptance of poor health status, and a sense of separateness from large metropolitan communities.[22] Additionally, mixed methods qualitative research, by including objective, quantitative data on disease and geographic factors is necessary to expand our understanding of the complex health challenges faced by people with COPD in rural areas. This also encompasses a need for qualitative research into facilitators and barriers to provision of care experienced by rural healthcare providers and rural health systems. Exploring the heterogeneous nature of rural health disparity through qualitative and mixed-methods research will improve our ability to understand the complex mechanisms behind disparate rural health outcomes.

Third, research in rural health disparity should utilize decentralized recruitment with embedded community research partners. Spoke-and-hub models for care, where a centralized pulmonary subspecialty team supports community partners in COPD diagnosis and management, have shown improved outcomes in COPD and in clinical trial recruitment. This practice is often referred to as “moving knowledge over moving people.”[20] Project ECHO (Extension for

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Community Healthcare Outcomes) is one exemplary spoke-and-hub model, providing subspecialty support for primary care providers in underserved communities in the Southwest.[35] Similarly, a "carousel" model of traveling multidisciplinary clinics that bring respiratory, nursing, and pulmonology support out to the community for regular respiratory disease focused clinics in conjunction with primary care providers have been shown to decrease exacerbations and improve management of patients with chronic dyspnea due to lower respiratory disease in the United Kingdom.[32] Analogous approaches should be integrated into the design of COPD research infrastructure and accompanied by a focus on implementation science to develop tailored clinical and research care models that meet the challenges of rural settings.

Lastly, interventions to improve rural health disparities should be designed by the community for the community. Improving recruitment of rural populations to clinical trials is essential to better understand the needs and limitations of caring for these patients. In their study focused on the recruitment and retention of a low-income, urban population, Huang *et al* identified several strategies for including often missed populations in clinical trials. Strategies to bolster recruitment and retention include partnering with local clinics and primary care providers to share spirometric and exercise testing data and to review COPD treatment plans for study participants. Additionally, they focused on including English and Spanish-speaking participants, using a broad definition of COPD to maximize inclusion of patients with respiratory problems, engaging an advisory board of participants to augment community-informed research protocols, and compensating subjects and community partners for their participation.[36] Similar strategies should engage rural and health disparity populations of patients and community members in order to understand values of these populations and ultimately improve participation in and generalizability of studies.

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Improving COPD research for people living in rural settings is an established goal of the COPD Action Plan of 2018. This deserves continued intensive attention moving forward as the healthcare gap between rural and urban residents continues to widen. We need new methodologies to study COPD in rural populations. Moving towards nuanced descriptors of rurality encompassing geographic distance, socioeconomic status, insurance access in addition to racial and ethnic health disparity will allow us to generate more informative clinical trials data. Specific considerations in study design can improve rural resident enrollment and retention in clinical trials. These approaches allow us to relinquish "rural" as a simple, categorical health descriptor in research, instead assessing the complex matrices of social determinants of health driving these disparate health outcomes.

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Declaration of Interest:

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Figure Titles and Legends

Figure 1. Strategies for improving research for disadvantaged rural COPD populations

Strategies for Improving Research for Disadvantaged Rural COPD Populations
Include distance as a covariate in clinical trial design
Use research tools designed to capture multidimensional assessments of societal and individual health determinants
Use qualitative research study design to assess cultural differences driving disparate outcomes
Use interventions designed by the community for the community
Employ spoke-and-hub or "carousel" models of recruitment
Incorporate implementation science to identify scalable, sustainable solutions and optimize healthcare delivery
Operationalize research partnerships to support primary care providers

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