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Letter to the Editor

In the south, if you give us lemons, we will make you lemonade



In February 2020 the MUSC Adult Cystic Fibrosis Center saw an average of 14 patients per clinic, many of whom traveled to our clinic in coastal Charleston, South Carolina (SC), United States of America (USA) from interior rural regions of our state including the towns of Hemmingway, Rockland, and Aiken among others. The majority of SC, including these towns, is designated as Medically Underserved and are designated as having Health Professional Shortages by the US Health Resources and Services Administration (HRSA). Patients from these towns must travel several hours to obtain the specialized care necessary for treating their rare and serious health issues. The socioeconomic factors that patients from rural areas of the USA experience have been shown to result in significant health disparities and adverse outcomes across multiple chronic diseases including diabetes, congestive heart failure (CHF), and COPD [1-4]. To address this reality, multiple interventions intending to break down the barrier of distance, including telemedicine and remote monitoring systems have been shown to be effective in these disease states, resulting in improved glycemic control, increased rates of appointment adherence, improved use of inhaled therapies, and decreased hospitalization [3-5].

The effect of living in rural USA on outcomes related to CF has not been fully explored; however, the effect of low socioeconomic status (SES) on CF have been documented and include more severe disease (worse pulmonary function and more frequent exacerbations), and increased mortality [6,7]. While lower SES may be one driver of poorer health status, rurality status and more broadly the individual's environmental context may be another important driver of negative health outcomes [6,8,9]. The trickle-down effect for people with CF living in poorly-resourced rural counties with limited financial capital and limited pathways for individual economic and social advancement may be significant; this is a hypothesis to explore in the world of CF care.

Our center is a participant in the Lung Transplant Regional Dissemination sponsored by the Cystic Fibrosis Foundation. Earlier this year, as part of this quality improvement initiative our group reviewed data for patients from our center who have ${\rm FEV_1}{<}40\%$ predicted, thus meeting criteria for referral for evaluation for lung transplant [10]. A total of 23 patients from our center were identified and among these patients 39% (9/23) live in a town classified as rural, 100% live in areas considered medically underserved, and on average these patients travel a distance of 198.2 miles round trip to our clinic.

On March 9th, 2020 the threat of the novel coronavirus, COVID-19, had become increasingly present in our community, and collectively our center moved to a 100% virtual care format, hoping to minimize the risk of exposure to our patients as well as to ourselves as health care providers. This transition has been nei-

ther easy nor seamless and like other centers we have experienced bumps in the road as we searched for the optimal platform for virtually visiting our patients. Most adult CF centers utilize a multidisciplinary approach to caring for CF patients, which commonly includes a physician, pharmacist, mental health counselor, social worker, nutritionist, and respiratory therapist among others (e.g., genetic counseling, research), making the move to a virtual platform particularly difficult. We have re-invented the way in which our pre- and post-clinic meetings are conducted, and like many others throughout the world, we now rely on videoconference formats for maintaining communication across our center. We are seeking to obtain home spirometers for our patients to provide objective data regarding their lung function without them having to come to clinic.

Amidst the tragedy created by COVID-19, a sudden and unexpected transformation of our clinic has occurred. Gone are the bland walls and cramped spaces of our outdated clinic rooms and in their place have been views of beautiful countryside in Hemingway and Aiken. We have been shown by our patients the farmland where they grow the food, we may one day eat at our tables. But it hasn't all been beautiful, a recent videocall provided a firsthand account of a patient's home where cardboard cutouts were used for window shades. We are also now seeing with our own eyes the realities of poverty that many of our patients live with

Together our team was galvanized by the tragedy unfolding as a result of the COVID-19 pandemic. Having been handed the sourest of lemons and truly missing the in-person patient experience, we are doing the best we can to make lemonade. Together we have found ways to take this tragedy and see it as a challenge to innovate the way we care for our patients. It has become increasingly clear that this is an opportunity to transform the way we traditionally deliver care and this will be particularly relevant to patients living in rural America. There is a strange irony that the isolation needed to fight this pandemic has allowed us to become closer to our patients in the most isolated regions of our state than ever before. For the first time ever, we are meeting with patients directly in their living rooms as we now provide "21st century house calls." The days of patients coming to a centralized clinic are likely over, or at least in the way we formerly knew it; even when a vaccine is identified for COVID-19, the shift in how we deliver medicine is likely to persist. However, we are committed to problem-solving ways to support our patients' physical, mental, and social health. As we move forward there are several key questions that we must ask and better understand including: Is telemedicine an effective and durable approach to providing multidisciplinary CF care, How can we effectively integrate the entire multidisciplinary approach in a telemedicine setting, Does distance to clinic affect the utilization and efficacy of telemedicine in CF, What is the role of rurality in our patient's health outcomes, and finally, does the utilization

of telemedicine mitigate negative outcomes related to rurality and poverty?

Declaration of Competing Interest

The Authors have no conflicts of interest related to this manuscript.

References

- Hartley D. Rural health disparities, population health, and rural culture. Am J Public Health 2004;94:1675–8.
- [2] Xu T, Pujara S, Sutton S, Rhee M. Telemedicine in the Management of Type 1 Diabetes. Prev Chronic Dis 2018;15:E13.
- [3] Au DH, Macaulay DS, Jarvis JL, Desai US, Birnbaum HG. Impact of a telehealth and care management program for patients with chronic obstructive pulmonary disease. Ann Am Thorac Soc 2015;12:323–31.
- [4] Carbo A, Gupta M, Tamariz L, Palacio A, Levis S, Nemeth Z, Dang S. Mobile Technologies for Managing Heart Failure: a Systematic Review and Meta-analysis. Telemed J E Health 2018.
- [5] Thomas RM, Locke ER, Woo DM, Nguyen EHK, Press VG, Layouni TA, Trittschuh EH, Reiber GE, Fan VS. Inhaler Training Delivered by Internet-Based Home Videoconferencing Improves Technique and Quality of Life. Respir Care 2017;62:1412–22.
- [6] McGarry ME, Williams WA 2nd, McColley SA. The demographics of adverse outcomes in cystic fibrosis. Pediatr Pulmonol 2019;54(Suppl 3):S74–83.
- [7] O'Connor GT, Quinton HB, Kneeland T, Kahn R, Lever T, Maddock J, Robichaud P, Detzer M, Swartz DR. Median household income and mortality rate in cystic fibrosis. Pediatrics 2003;111:e333–9.
- [8] Harris JK, Beatty K, Leider JP, Knudson A, Anderson BL, Meit M. The Double Disparity Facing Rural Local Health Departments. Annu Rev Public Health 2016;37:167–84.

- [9] In: Le Menestrel S, Duncan G, editors. A Roadmap to Reducing Child Poverty. Washington (DC): 2019.
- [10] Ramos KJ, Smith PJ, McKone EF, Pilewski JM, Lucy A, Hempstead SE, Tallarico E, Faro A, Rosenbluth DB, Gray AL, Dunitz JM, Committee CFLTRG. Lung transplant referral for individuals with cystic fibrosis: cystic Fibrosis Foundation consensus guidelines. J Cyst Fibros 2019;18:321–33.

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