COVID-19 Reflections

We Are Not OK: Safety Net Primary Care Access in a Non-Expansion State Amid COVID-19

In North Carolina, rural health care—especially the primary care safety net—is a remarkable but under-resourced vital support system. COVID-19 stressed that already precarious system. While the acute COVID-19 crisis may be receding, we are concerned about the long-term effects of the pandemic on both individuals and the rural primary care safety net.

Introduction

In March 2020, life for many North Carolinians began to pivot toward living alongside the threat of COVID-19. Every familiar dynamic was turned on its axis, requiring quick improvisation and problem-solving from every sector. The health care landscape in rural North Carolina pre-COVID was already a house of cards, precarious and resource-scarce. Providers and staff were, and remain, exhausted from the many stressors on their patients and communities [1]. This was only amplified in the primary care safety-net community, especially in organizations like Roanoke Chowan Community Health Center (RCCHC), a federally qualified health center (FQHC) based in Ahoskie, North Carolina. FQHCs like RCCHC serve patients regardless of ability to pay, and provide multiple services under one roof: primary care, behavioral health, prescription assistance, and many other types of care. FQHCs are located in medically underserved areas—places where people were already in great need of health care before COVID-19 came along. RCCHC exists in northeast North Carolina. In 2017, 23.09% of Eastern North Carolinians reported their health as "poor or fair" compared to 18.47% of citizens in the rest of the state [2]. In addition, age-adjusted death rates are substantially greater in Eastern North Carolina than the rest of the state for virtually all major causes of death [2]. North Carolina is already 34th in premature death; if just Eastern North Carolina was compared to the rest of the country, the ranking would fall to 42 [2]. FQHCs faced challenges staffing rural locations before the pandemic. Workforce challenges only worsened as health care professionals became exhausted from handling COVID-19, facing their own traumas yet continuing to try to help patients face the same things. FQHCs never stopped serving patients—in fact, we worked twice as hard. But under the financial, health, and psychological strains of the pandemic, only creative problem-solving and a commitment to serving patients no matter what kept FQHCs like ours running.

December 1, 2020, was a happy day for Deborah, a patient at RCCHC. A single mother of two daughters, she was celebrating her 60th birthday. As a 14-year breast cancer survivor, every birthday is cause for celebration for Deborah, a magistrate judge in Eastern North Carolina. She practiced social distancing, masking, and was intentional about limiting contact with others. But she still had to do her job. Unfortunately, just a few weeks after her birthday, she began to experience respiratory symptoms, and since the holidays were coming up, she determined it best to get a COVID test and see her primary care provider. Her COVID test was positive and she was sent home, but within a few short days her condition worsened. Deborah lives alone, and when she had the scary realization that she was having a hard time breathing, she called a friend who advised her to call 911 immediately, which she did.

On December 20, Deborah was transported by EMS to the local hospital, which was overrun with COVID patients. She was kept in the emergency

Electronically published May 2, 2022.

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N C Med J. 2022;83(3):194-196. 0029-2559/2022/83317

department for over two days due to lack of beds on the rural hospital's COVID-19 floor. She was on high levels of oxygen and was left alone for hours at a time—a commonplace happening at many hospitals that were overrun with sick patients. Deborah's time in the ED was tremendously hard and very lonely. She felt her COVID pneumonia was worsening, she was barely eating, and she was dehydrated. Deborah spoke with several friends and family from the hospital, and one brought her a phone, which she used to catch up with this article's coauthor, Kim. Upon hearing how low Deborah was, physically and mentally, Kim stayed on the phone with her while using a second phone to call contacts at the hospital and express grave concern about her friend. Finally, Deborah was transferred to the hospital's COVID floor the evening of December 22, 2020. She was treated and then discharged on Christmas Day. She had to use a cane for several weeks after being discharged due to fatigue, joint weakness, and pain. Deborah believes if there weren't so many very sick COVID patients needing hospital beds, she would have stayed another day in the hospital. When everyone is very sick at once, hospitals must let patients go home at an earlier stage in their journey to recovery—not great for any individual at any time, but compounding the trauma of the pandemic and its long-term health effects.

As a patient at RCCHC, which provides COVID nurse case management services, Deborah received daily calls for two weeks upon discharge from the hospital, along with an in-person visit with her primary care provider. However, like hospitals, FQHCs were overburdened and understaffed at this time, and RCCHC was only able to speak with her once per day. She was also lucky that her daughter could care for her at home. Deborah is Black, has preexisting conditions—including hypertension and prediabetes—and lives in a rural area. Though she has private insurance, many others like her fall into the Medicaid coverage gap in North Carolina, which has not expanded Medicaid [3]. Even with the care received from medical providers and attentive family, Deborah was forced to be away from her work, which did not offer medical leave, from the time of her discharge from the hospital through the end of February 2021. Her fellow magistrates covered for her. She then returned to work on a phased-in schedule, with restricted hours for an additional 30 days; because she worked a range of shifts upon returning to work, her fatigue was intense. Prior to her COVID diagnosis, Deborah was physically active and had no restrictions in mobility. Thus, she describes the time after her discharge when fatigue and pain limited her mobility as very challenging.

Deborah has lived the data, which show that racial and ethnic minority groups with the referenced conditions are at even higher risk for severe COVID-19 illness [4]. Race and ethnicity are risk markers. In other words, race and ethnicity are hardly the causes of poor health outcomes; instead, folks with these markers are more likely to experience health challenges due to other factors that impact health, including socioeconomic status, lack of access to health care, and increased exposure to the virus due to occupation. An estimated 70.4% of adults in North Carolina are at higher risk for severe illness from COVID -19 based on being aged 65 or older, having at least one underlying health condition, or both [5]. These are overwhelmingly the kinds of patients who go to FQHCs for care, as these facilities accept all patients regardless of ability to pay. FQHC patients without insurance are asked to pay as they are able, on a sliding-fee scale. It is our experience that patients want to participate in their own care, whether that is by having "skin in the game" and paying on the sliding scale, or actually governing the operations of their health care organizations. FQHCs are unique in that they are governed by at least 51% patient-led boards. Those patients guide and lead the care for their own communities. Deborah is not only a patient at RCCHC; after beginning as a sliding-scale patient and joining RCCHC's board, she later gained insurance through her job and is now chair of the RCCHC board.

Deborah was fortunate in some ways, but she has experienced long-term effects of her COVID-19 illness. She likely suffers from a varied set of symptoms that may be indicative of a not-yet-well-defined syndrome colloquially known as "Long COVID" [6].

Even though Deborah has returned to her work and community obligations, she feels that she may never go back to being quite like she was before the pandemic. Currently, she has a spot on her lung that her pulmonologist has told her is likely a result

of COVID and must be checked every 12 months, adding to her anxiety about the long-term effects of the disease. On top of that, insurance companies, including her own, made decisions without explanation about when they would stop covering COVID treatments. Thus, some of Deborah's bills were not paid for under COVID coverage, even though her symptoms came after her COVID diagnosis. Complicated billing structures add to the confusion of the already fragile rural health system.

The rural health care infrastructure of North Carolina was not whole before the pandemic, and will not return to its before-pandemic state any time soon. FQHCs and rural hospitals have had providers and frontline staff quit due to their own illness and to the stressors of working through a pandemic. Rural health care facilities had to stretch limited resources in so many directions at once, as FQHCs continued primary care via telehealth in the early days, while arranging testing and vaccine events as trusted community partners. They continued to deal with North Carolina's many health challenges, such as the lack of Medicaid expansion, the substance-use epidemic, and trying to continue to provide the best care to patients with all kinds of chronic and acute conditions. State and federal lawmakers have seen the struggle and have provided some funding to FQHCs. This recovery will involve more than just money. Legislation, proactive policy, and permanent funding for FQHCs are all essential.

Researchers have already noted that the treatment of Long COVID is "exposing some of medicine's enduring weaknesses" [6]. As we know in community health, chronic illness is best treated with a long-term relationship with a trusted community provider. Just like other chronic conditions (e.g., diabetes, obesity, high blood pressure, colorectal cancers), Long COVID or conditions following COVID infections may send patients to specialists. It is clear that it will affect both physical and mental health. It will require addressing social drivers like paid time off and access to health specialists, good transportation, locally available and affordable fresh food, and more. Proposed solutions to these systemic weaknesses, such as COVID case management and involving patients in the decision-making process, are solutions already practiced by FQHCs.

It is time to listen to our patient-leaders, who are telling us that they are not OK; we are not OK. NCMJ

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Acknowledgments

Disclosure of interests. Kim Schwartz is the CEO of Roanoke Chowan Community Health Center where Deborah Morrison is a board member and a patient. Leslie Wolcott is an employee of the same organization. No further interests were disclosed.

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