

## Trust and the Test: Producing Narrative Certainty in an Evolving Pandemic

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By

*“COVID is the thing that works differently. It’s not our experience of the illness that works differently.”*

A recent observation by Hannah Alcock

We both spend a lot of time in hospital Emergency Departments (EDs). We know the moods, the smells, the human tableaux played out in a loop with each new intake, each new shift. As a medical anthropologist, Jennifer frequently passes through EDs located anywhere from Boston to Atlanta for her research on opioids and overdose. Hannah is a certified nurse technician and an EMT-B. She works in a pediatric ED at a hospital in an urban area of North Carolina while completing her bachelor’s degree in public health. On paper, we do very different kinds of work. In a more practical sense, however, we both pursue the same goal: as Clifford Geertz once quipped, we strive to figure out what the devil the people around us in the ED think they are up to.

The hospital where Hannah’s pediatric ED is located is one of the few locations in our region of North Carolina where individuals can receive diagnostic testing for the novel SARS-CoV-2 virus. When the earliest tests became available, parents engaged in a veritable scramble to get their kids tested. The fresh panic of the pandemic combined with a limited capacity for testing created a demand that far outstripped supply, leaving many feeling angered, violated, and scared. In a recent contribution to *Somatosphere*, [Alice Street and Ann H. Kelly](#) traced this social discontent with diagnostic testing capacity in the U.S. back to its origin point: the biomedical “fiction” that testing is readily available, and that the test simply and reliably “works.” Testing also holds social value, they argue, as a source of certainty in uncertain times. They write:

In the consultation room, the traditional role of diagnosis is to establish what is wrong with an individual patient. In an outbreak scenario, the primary purpose of diagnosis is to know ‘who has *it*’; to distinguish people hosting a specific infectious pathogen from everyone else, sick or healthy.

Testing, in this pandemic sense, felt like a defense against an unknown threat. Testing promised an ontological—and also perhaps performative—guarantee that our questions about our physical health are fundamentally answerable, and that a true answer to those questions is right at hand. In blunt terms, North Carolinians were desperate to know whether their kids were safe, and the test offered an allure of certainty.

With time, however, as weeks that have felt like years passed by and we have begun normalizing to our new, peri-pandemic reality, new patterns have begun to emerge in the pediatric ED. Many children come to the ED who are visibly ill, often presenting with symptoms known to be associated with COVID-19. These children often could not receive a diagnostic test for the SARS-CoV-2 virus. In the earliest weeks of the pandemic, strict requirements had to be met, such as known contact with another infected person, in order for testing to be ordered. Therefore, some children left the ED with a presumptive diagnosis of COVID-19 but were unable to receive any laboratory-confirmed testing.

As testing became more available, and families were able to receive initial results in a matter of hours, initial test results could come back inconclusive or be positive only to later be contradicted by confirmatory testing that showed clearly negative results. The tests are imperfect. The virus can be hard to detect. Nothing about this scenario is unusual. What captured our attention, though, was how frequently the parents of such children—clearly symptomatic yet without a clear diagnosis—left the ED to quarantine at home appearing fully satisfied with this clinical ambiguity. Throughout both of our professional careers, we have seen adult patients and the parents of pediatric patients, alike, respond to inconclusive diagnoses with a fervent advocacy for more clinical work. Biomedicine's aura of factuality so often empowers us to demand definitive knowledge of our physical states. We want to positively know if we have this or that disease. The parents who left the pediatric ED in possession of both a calm satisfaction with their predicament and a fundamentally undiagnosed child appear in stark violation of this principle.

Similarly confounding were the parents who brought perfectly healthy-looking children to the ED with some kind of accidental injury—kids who had tripped and broke a wrist while running through the kitchen, for example—but left with a completely unexpected yet laboratory-confirmed diagnosis of SARS-CoV-2. While hospital staff assessed the child's injuries, a medical history would be taken. It might be discovered, for instance, that a grandparent had been providing childcare while the parents worked, and that this grandparent had been under the weather for a week or so. Also, upon being asked by medical staff, the child might admit to a tummy ache that they had not previously reported to their parents or had otherwise not drawn notice. This would result in

a SARS-CoV-2 test being ordered, and that test would occasionally come back, to the shock and consternation of the entire family, conclusively positive.

In contrast with those parents of sick children with an inconclusive COVID-19 status, the parents of asymptomatic children often seem to struggle with the unwelcome certainty that the test results have produced. Though a confirmed diagnosis of SARS-CoV-2 infection is surely not welcome news to anyone, the assurance that testing ostensibly provides is not given the epistemological value by these parents that an overly-simplistic read of [Street and Kelly](#) might lead one to predict. Instead, these adult family members seem eager to begin assailing the alleged unassailability of the test. Some disbelieve. Some bargain. Some deny. And hospital staff are suddenly engaged overtime to help these parents accept the reality that their child needs to be quarantined, that they might have to stay home from work, that a complication they never planned for is now very much ruling their lives.

These scenes, increasingly common in Hannah's pediatric ED, reveal a nuance in our social relationships with COVID-19 and diagnostic testing. First, the risks faced by children in the COVID-19 pandemic were not held in equal esteem by all parents. Some brought symptomatic children to the ED in a panic that they might have contracted the virus; others brought their injured children to the ED with no concern for the infection risk of that hospital environment. The objective results of diagnostic testing can, therefore, trouble the risk narratives of the parents to very different degrees. Furthermore, the symbolic weight of testing shifts when we move between questions of population health and individual wellbeing. When testing can serve as an information source about our risk environment, when testing can be deployed on a massive scale to tell us where the virus is concentrated or who amongst us is most at risk, the test can reduce a society-wide uncertainty, answer questions, and resolve fears that are widely shared. After all, the stories that we tell about the populations around us are often cloaked in statistical trends and measurements. We know how to parse these data. On an individual level, however, the externally produced reality of a test result must contend with many more symbolic registers. We must find ways to square that result with our understanding not only of the risk environment in which we live but also with the intimate, embodied experiences—our own or, perhaps, our children's—with which we are so familiar. In other words, when a test result indicates something about our own, individual bodies—there is a deeper, embodied knowledge about whether or not we are sick must be made commensurate with the test results for our lived experiences to make sense.

Making sense of our experiences requires, in large part, the crafting of

coherent stories about what is happening to us. We have to produce meaning out of things for which meanings are not yet settled. Medical anthropologist [Zane Line-Ozola has theorized](#) that the constant flurry of meaning-making—the classification of objects, spaces, activities, proximities, and bodies into categories of risk—in response to the seemingly unknowable nature of the SARS-CoV-2 virus acts a collective attempt on all our parts to render the virus knowable and therefore containable. This knowledge we produce symbolically ostensibly holds the promise of control, of successful risk management, of the ability to achieve “the Pasteurian dream, of pure social relationships without a third [pathogenic] agent.”

Life during the COVID-19 pandemic has felt, at times, like an onslaught of symbolic work as we labor to make the realities of the pandemic commensurate with our cultural narratives and lived experiences. In the earliest days of the pandemic, [Kate Mason rightly observed](#) that the politically motivated habits of state authorities in perceiving, acknowledging, and responding to invisible threats shape pandemics as much as the biological mechanisms of viral transmission. [Kimberly Sue has repeatedly called attention](#) to the tenacity of our beliefs about the risks posed by “bad guys” in prisons to override our stories about the risks of COVID-19, fostering complacency for the profound structural violence meted out on incarcerated populations in this pandemic. [Maryam Banikarim has discussed](#) how community identity and engagement have changed as a result of COVID-19, how our own identities as neighbors evolve as we come to better know and understand who our neighbors are. In this online forum, [Adia Benton has shown](#) how political and racialized narratives have been applied to the COVID-19 pandemic to ensure these events conform to:

...the [conventional outbreak narrative](#), where a new, deadly virus emerges in the scandalous co-mingling of Asian or African native species and ‘man’, circulates along well-traveled business routes, and is unleashed on the Western world through illicit intimacies occurring on multiple registers.

In sum, we try to find what comfort or certainty we can by forcing the bits of knowledge we do have about the virus into the narratives we already know, the stories that already make sense, because nothing is so deeply, psychologically unsettling as lived experience that has no coherent story.

Parents in the pediatric ED likewise strive for coherence between the structural and the personal. Of course, we expect the test to be widely available and my child should definitely receive one, but how can they be sick when they aren’t actually sick? Yes, we expect the test to work,

especially when give to my child, but how can a test come back negative when they are so clearly and seriously ill? Despite the allure of certainty that diagnostic testing appears to embody, the results of diagnostic testing, when performed on individual bodies, presents this confounding possibility that clinical fact and bodily experience may be at odds.

In the wake of this ontological conflict—diagnostic tests telling them one thing and their children’s bodies telling them another—parents in the ED often seek a path forward that is clear and coherent, and that responds above all to the embodied realities of their child’s health, which exist right in front of them. For the parents of children who appear healthy but test positive for SARS-CoV-2, these test results represent an unexpected and unwelcome disruption. Accepting the positive diagnosis means staying home and quarantining with their child, who is not acting sick. It could mean separating from the family they have relied on for childcare. It could mean missing work. It could mean losing income, losing financial stability, putting the entire family at risk. For these parents, learning that the test is unreliable would be good news. A laboratory confirmed diagnosis certainly provides the social justification for taking these actions, but can every job, every employer be relied on to be as generous? Such questions fuel the bargaining and the disbelief that puts hospital staff’s medical and social work skills to the test. Any thread of uncertainty in the positive result is a thread that parents, quite understandably, want to unravel until every alternative explanation is exhausted.

For the parents of sick children with inconclusive or negative SARS-CoV-2 tests (or, early on, no test results at all), the narrative weight of COVID-19, its pervasiveness in media, in public discourse, in our lives, acts as a stand-in for the assurance that testing ostensibly promises to provide. The children are so sick, their symptoms so severe. They present like cases of COVID-19. Even if the test is negative, even if there is no test, what else could this illness possibly be? Their medical care won’t change. There is still no medical therapy specific to the treatment of COVID-19. Healthcare providers will respond to and treat the symptoms of COVID-19 the same way they would treat those symptoms in any patient with any other illness. For parents, this reality can be empowering, rather than discomforting, as many confidently possess the skills to manage COVID-19’s more minor symptoms in their children in their own homes or are ready and willing to learn with support from hospital staff and local nursing hotlines. Children who are able to go home will be sent home to quarantine, their parents assured that they don’t need the intensive care the hospital offers. Children who require more intensive intervention will be admitted to the hospital for inpatient care. The plan of action won’t fundamentally change. The sick role is clear. The marching orders firm. That the child

probably does have COVID-19 is a story that everyone can support.

Though many of us do, as [Street and Kelly](#) observed, “[expect] too much from diagnostic technologies,” these scenarios illustrate how the potential *unreliability* of diagnostic testing, the discrete possibility of false positives and false negatives. This creates discursive space in which parents can negotiate with the facts that biomedical technologies produce, and contest the stories those facts construct about the health of their children. Parents engage this slippage to create meaning about their children’s health with not only biomedical but also social, emotional, and bodily salience. And that salience emerges directly from narratives of doubt in the reliability of diagnostic tests.

One might be led to wonder how the findings of diagnostic technologies could be dismissed so readily in a culture that fervently centers biomedical knowledge and practice. But a fundamental insight brought to bear on questions of health and illness by critical medical anthropology is this: the stories that we tell about our health don’t have to conform to the rules of biomedical science; they just have to make sense to the people who are telling them. This was Arthur Kleinman’s great insight in his book [The Illness Narratives](#): the same constellation of symptoms can lend itself to multiple, sometimes contradictory explanatory models of a particular illness episode. Some of those models might be strictly biomedical in their logic. Others may not. But they all reveal, in one way or another, our tolerance (or lack thereof) for things that cannot be explained or that contract the explanations in which we’ve already invested.

By considering the challenges faced by parents in this pediatric ED and the discursive work they pick up in response to those challenges, we can gain a deeper appreciation for the human capacity to render meaningful experience out of the most confounding situations. Even under biomedicine’s long shadow of technological certainty, we are capable of undertaking a rich, cultural, even clinical bricolage for the sake of building truth where there isn’t necessarily much certainty to offer. Yes, biomedical and diagnostic technologies offer us the allure of certainty. When given a choice between coherence and confusion, we choose coherence. When many stories are available to us, we choose the story that makes the most sense. Perhaps that is the thing that connects us, the drive we all share in our human condition in the midst of a pandemic that would seek to drive us apart.

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[Jennifer J. Carroll](#), PhD MPH, is an assistant professor of anthropology at Elon University. Her first book, *Narkomania: Drugs, HIV, and Citizenship in Ukraine, details the lived experience of drug use and role of addiction treatment in establishing—and disrupting—sovereignty in Ukraine’s 2014 revolution and ongoing war with Russia.*



*Hannah Alcock is a recent graduate of Elon University's Public Health Studies Department with a sociocultural focus and minor in poverty and social justice. One of her notable undergraduate projects included structuring the development of an opioid case review team for Alamance County through the local health department and collaboration with other local and state agencies. She is also a certified EMT-B and Nursing Assistant in North Carolina with practical experience working in both Pediatric and Adult Emergency Departments at the local trauma center.*

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