

## Impact of Lack of Testing on Patient Recovery in the Early Phase of COVID-19: Narratively Collected Perspectives from a Remote Monitoring Program

**Authors :** Nicki Mohammadi, Emma Reford, Natalia Romano Spica, Laura Tabacof, Jenna Tosto-Mancuso, David Putrino, Christopher P. Kellner

**Abstract :** Introductory Statement: The onset of the COVID-19 pandemic demanded an unprecedented need for the rapid development, dispersal, and application of infection testing. However, despite the impressive mobilization of resources, individuals were incredibly limited in their access to tests, particularly during the initial months of the pandemic (March-April 2020) in New York City (NYC). Access to COVID-19 testing is crucial in understanding patients' illness experiences and integral to the development of COVID-19 standard-of-care protocols, especially in the context of overall access to healthcare resources. Succinct Description of basic methodologies: 18 Patients in a COVID-19 Remote Patient Monitoring Program (Precision Recovery within the Mount Sinai Health System) were interviewed regarding their experience with COVID-19 during the first wave (March-May 2020) of the COVID-19 pandemic in New York City. Patients were asked about their experiences navigating COVID-19 diagnoses, the health care system, and their recovery process. Transcribed interviews were analyzed for thematic codes, using grounded theory to guide the identification of emergent themes and codebook development through an iterative process. Data coding was performed using NVivo12. References for the domain "testing" were then extracted and analyzed for themes and statistical patterns. Clear Indication of Major Findings of the study: 100% of participants (18/18) referenced COVID-19 testing in their interviews, with a total of 79 references across the 18 transcripts (average: 4.4 references/interview; 2.7% interview coverage). 89% of participants (16/18) discussed the difficulty of access to testing, including denial of testing without high severity of symptoms, geographical distance to the testing site, and lack of testing resources at healthcare centers. Participants shared varying perspectives on how the lack of certainty regarding their COVID-19 status affected their course of recovery. One participant shared that because she never tested positive she was shielded from her anxiety and fear, given the death toll in NYC. Another group of participants shared that not having a concrete status to share with family, friends and professionals affected how seriously onlookers took their symptoms. Furthermore, the absence of a positive test barred some individuals from access to treatment programs and employment support. Concluding Statement: Lack of access to COVID-19 testing in the first wave of the pandemic in NYC was a prominent element of patients' illness experience, particularly during their recovery phase. While for some the lack of concrete results was protective, most emphasized the invalidating effect this had on the perception of illness for both self and others. COVID-19 testing is now widely accessible; however, those who are unable to demonstrate a positive test result but who are still presumed to have had COVID-19 in the first wave must continue to adapt to and live with the effects of this gap in knowledge and care on their recovery. Future efforts are required to ensure that patients do not face barriers to care due to the lack of testing and are reassured regarding their access to healthcare. Affiliations- 1Department of Neurosurgery, Icahn School of Medicine at Mount Sinai, New York, NY 2Abilities Research Center, Department of Rehabilitation and Human Performance, Icahn School of Medicine at Mount Sinai, New York, NY

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