

# Privacy, or the Lack Thereof, and Its Implications for Dignity in Mobile COVID-19 Testing

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## Abstract

**Introduction:** Chicago's COVID-19 Rapid Response Team (CRRT) is a decentralized, interprofessional group of nurses, residents, students, and faculty who provide free COVID-19 testing for those living or working in congregate settings (i.e., shelters, long term care facilities, prisons and encampments) due to their increased risk. Individuals within these vulnerable populations regularly experience stigma, a lack of privacy, and healthcare discrimination as they are often in low-income and underserved communities. The CRRT tests in settings that are necessarily large (cafeterias, meeting areas, gymnasiums, recreation rooms), and provide little physical privacy. Regardless of patient circumstances, respecting patient dignity is a professional standard of care, and patient privacy is consistent with that standard.

**Methods:** Guided by trauma-informed care techniques, emancipatory nursing practice, and cultural safety methodology, student members of the CRRT initiated a project focused on expanding physical privacy protection for those undergoing COVID-19 testing.

**Conclusion:** Though the introduction of a portable privacy screen started as an initiative to safeguard the dignity for underserved populations, this call to action implores current and future health care providers to prioritize the ethical treatment of those most vulnerable by advocating for patient dignity and privacy.

## Keywords

COVID-19, testing, privacy, underserved, community, trauma

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## Introduction

COVID-19, a highly infectious disease deemed a world-wide pandemic in March of 2020, continues to surge and threaten lives in the US. Since January 2020, Illinois has seen over 1,200,000 cases and 21,251 deaths (as of 3/28/2021, IDPH), with the City of Chicago accounting for 253,962 of those cases (from 3/1/20-3/26/21, City of Chicago). Similar to other large cities within the US, Chicago is full of “testing deserts” —primarily Latino and Black, low-income communities where the virus is spreading the fastest and more testing is necessary due to limited availability of testing sites or testing site hours, which perpetuate COVID-19 disparities (Credit, 2020; Dizikes & Palomino, 2020).

An urgent need for high-impact responses to Chicago's rising case numbers in Spring, 2020 prompted a mobile testing initiative: the COVID-19 Rapid Response Team (CRRT). The CRRT, an interdisciplinary collaboration between University of Illinois Chicago, Rush University and the Chicago Department of Public Health, provides trauma-informed COVID-19 testing for people living in congregate settings. These include homeless shelters, long-term

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care, correctional centers, and residential treatment facilities. Due to the living conditions within them, people living and working there are at increased risk for contracting COVID-19. Many of these populations are further impacted by systemic, socioeconomic and structural barriers such as lack of access to healthcare resources, to jobs that provide living wages and to quality education (Purkey & MacKenzie, 2019). These inequities further increase their risk and disparities, which the CRRT tries to reduce by informing people of their status. As people of color, the majority of those tested by the CRRT come from communities who have historically experienced trauma with respect to medical interventions (Warren et al., 2020). The standard of care among CRRT members is to utilize trauma-informed approaches by acknowledging the past historical trauma (i.e., Tuskegee) and the present trauma of this virus. Beyond that, our team acknowledges that “within systems serving low-income populations (e.g., child welfare, homelessness), traumatic stress may be nearly universal” (Bassuk et al., 2017). Therefore, our team members are trained to offer choices to our patients, reinforcing their own control over their bodies, and teaching them testing techniques if they prefer to do it themselves. All of these are considered aspects of trauma-informed care (as described by Bassuk et al., 2017) and are crucial for trust-building in populations who have been traumatized.

Nurses have a professional responsibility to promote the dignity of their patients; we are trained to protect the physical privacy by shutting doors, closing curtains, or draping sheets over our patients so as to minimize their feeling exposed. Mobile testing, like that provided by the CRRT, occurs in large recreation rooms, gyms and cafeterias, where there is often a lack of physical privacy. As practitioners of trauma-informed care, we wanted to avoid re-traumatization and to promote dignity for all patients (Menschner & Maul, 2016). We felt strongly that the lack of privacy inherent in the conditions where we were testing could serve to compromise that dignity. To build trust and support patient dignity, our team designed a small project to determine if privacy screens, a simple and inexpensive solution, would foster trauma-informed and dignity-preserving care.

## Discussion of the Topic

The CRRT responds to surging cases in Chicago by providing COVID-19 testing. Until mid Fall 2020, the CRRT conducted COVID-19 testing through oral-nasopharyngeal swabbing. During the specimen collection, a swab is inserted into the nasopharyngeal cavity as well as the back of the throat, which tends to initiate a gag reflex. A COVID-19 specimen collection is often done in private, however, given the constraints of the

facilities we serve, patient privacy had not been prioritized. Disregard for the privacy and dignity of those most vulnerable has occurred repeatedly throughout medical history, in events such as the Tuskegee Syphilis study, where Black men were enrolled in the clinical research, needlessly suffered and died long after a cure was found (Frakt, 2020). In addition to COVID-19, the Black Lives Matter (BLM) movement has highlighted systemic racism and injustices people of color face. The intersections of COVID-19 and BLM must trigger a critical self-examination among public health practitioners to not further retraumatize patients of color. We were unwilling to be complicit in the institutional and structural barriers which have infiltrated the healthcare system and facilitated such health disparities.

Current literature surrounding patient privacy focuses on the patient's *health information*, rather than their physical privacy. While HIPAA Privacy Rule safeguards patient privacy related to medical records and health information (Health and Human Services, 2020), HIPAA does not have standardized protocol for protection of physical privacy. Regardless of whether a patient acknowledges a lack of privacy, it is, nevertheless, the nurse's responsibility to protect patients: “*The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person*” (American Hospital Association, 1992; American Nurses Association, 2015).

In keeping with a patient's right to privacy, the nursing students working with CRRT initiated the use of a privacy screen to align with culturally safe, trauma informed care, and emancipatory nursing practice (Kagan et al., 2014). This project acknowledges how patients' physical privacy should be inherent to our nursing practice (Ozturk et al., 2014). By expanding physical privacy protection for patients and staff getting tested for COVID-19 by the CRRT, we are making a clear statement that both their safety and their personal dignity matters (Rabiega-Przylecka, 2012). Ensuring patient privacy can be viewed as a sign of respect for the patient's dignity (Ghasemi & Valizadeh, 2019). In order to rebuild trust in a healthcare system which has historically ignored or harmed those most vulnerable (Nix, 2017; Spigner, 2019), the CRRT opts to foster privacy during COVID-19 testing and support the dignity of those most vulnerable. Omerov et al. (2019) addresses how culturally safe care for those impacted by housing instability can positively impact a willingness to access care in the future. By advocating for patient privacy through the use of a privacy screen during COVID-19 testing, CRRT members acknowledge that positive health experiences can positively influence health and minimize healthcare disparity.

Oronasopharyngeal testing for COVID-19 is invasive and can be painful. Even with our team using trauma-

informed care methods, patients have been visibly afraid, cried, squirmed out of their chair, gotten angry and violent by screaming, swearing and kicking. Due to the fact that we often set up in cafeterias, meeting areas, recreation rooms, or other necessarily large spaces in the facilities we serve, these frightened and angry responses were on display for their friends, acquaintances and colleagues to see. These responses may further ignite fear within populations that are wary of trusting the medical system.

CRRT members felt the privacy offered was inadequate and inconsistent with the mission to provide culturally safe, trauma-informed care. While patients did not identify this lack of privacy as concerning, the CRRT team wanted to align with culturally safe practices by facilitating patient physical privacy in support of patient dignity.

We performed a root cause analysis to determine why we were not offering patients more privacy. We determined through our analysis that not only was there a problem with the spaces we were testing in (as described above), but a problem with our own space; because we were a mobile unit without a central “home office,” all of our equipment needed to fit in the trunk of a car. Additionally, privacy screens were rarely provided by the testing facilities.

We researched multiple options for privacy screens. Ideally, they would be small and packable as well as sturdy, cleanable, and inexpensive. A photography backdrop set-up costing \$35 suited our purpose, dimensions and finances. It could be adjusted to a height of 6.5 ft, and a length of 10 ft, but its dimensions when broken down ( $33.5 \times 6.5 \times 4$  inches) made it portable and storable.

After setting up the privacy screen to separate patient intake from patient testing, team members and patients reported that an adequate level of privacy was provided. Team members expressed that they were better able to provide enhanced culturally safe care that honored the patients’ dignity. Additionally, we hoped that by creating a positive, professional encounter with regards to COVID-19 testing we might help patients whose healthcare experiences had been less than respectful in the past inch toward a rebuilding of trust of the healthcare system, which would increase health outcomes, such as participation/acceptance of the COVID-19 vaccine, for that patient in the long run (Warren et al., 2020). Regardless of whether patients may be accustomed to a disregard of their privacy, as nurses, it is incumbent upon us to work to protect it and advocate for our patient’s dignity.

## **Conclusion: Small Intervention With Big Implications**

Humanitarian crises, such as COVID-19, require rapid response and innovative thinking to better protect

patients. The COVID-19 global pandemic required public health practitioners to expeditiously launch primary and secondary prevention protocols intended to stop the spread of the virus. CRRT is a key component of such prevention efforts within Chicago because when public health experts advised people to stay home, CRRT was deployed to ensure congregate settings called “home” by many would not become an incubator for the virus. Through our work, we were able to identify people who had COVID-19, isolate them and ensure that they received the care that they needed. We were instrumental in helping institutions stop clusters or reduce the impact of outbreaks within their facility, communities and families. Yet, the rapidity with which the team was mobilized and our efforts scaled was not an excuse for abandoning the ethical foundations of our collective public health nursing practice. In order to be culturally safe and trauma-informed, we needed to reevaluate how we were preserving or endangering the dignity of our patients (Curtis et al., 2019; Richardson et al., 2017). As such, this privacy screen was necessary to protect patient privacy.

The team’s focus and reevaluation on the physical privacy of those being tested was an outcome of the trauma-informed, culturally safe and emancipatory approach. Together we can foster the trust necessary for practitioners and the public to partner to respond effectively to a public health crisis. With relatively simple interventions, such as privacy screens, health care providers can enhance the public’s trust in a time when that trust was eroded due to confusing guidance and misinformation as the world struggled to understand this novel virus. The privacy screens are the physical symbol of the authentic engagement that the CRRT team members brought to each interaction however brief they were (Lindwall & Lohne, 2020; Stanley et al., 2020). The CRRT provides a model for how an interdisciplinary team of public health practitioners can respond rapidly and nimbly to the public need, while remaining authentic to our values: specifically, those regarding patient dignity.

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