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A Path Towards Digital Equity

Telemedicine is a vital tool in health care, but it's leaving some patients behind. Jefferson researchers are on a mission to improve 'digital readiness' in under-resourced communities to bridge inequities.

BY **KARUNA MEDA** | ILLUSTRATIONS BY **ERIN K. ROBINSON**

I t was the beginning of March 2020, and Chelsea Torres had just returned home to Philadelphia from college for spring break. A few days into her stay, everything changed. Whispers of a deadly pathogen had turned into full-throated cries of caution, and the country went into lockdown. Chelsea and her parents were alarmed when they began to feel unwell — vague symptoms that they probably would have chalked up to a cold in any other circumstance. But amidst the novel coronavirus, they didn't want to take any chances, and hastened to get tested. An agonizing few days of waiting confirmed their suspicions — they had COVID-19. Soon, they began to hear of more cases in their tight-knit Latino community. Many of their family members and friends had underlying health conditions and/or were essential workers and therefore at higher risk of contracting the virus — it was the first glimpse into the disproportionate impact COVID-19 would have on the community. Like many in the diaspora with relatives living abroad, they also grew concerned about their family back in the Dominican Republic.

Over the next few days and weeks, Chelsea and her parents navigated the uncertainties of trying to get care. This meant using telemedicine, which many healthcare centers had transitioned to. Chelsea used her smart phone and computer routinely, and had already adjusted to online learning; using telemedicine didn't daunt her. But her parents weren't as accustomed to technology, and needed her help accessing patient portals and setting up video visits. There was something else that was holding them back that Chelsea couldn't quite put her finger on; it seemed like mistrust and apprehension about this new form of medical care.

A couple of miles away at Jefferson Health, Kristin Rising, MD was noticing something similar.

The Digital Divide Includes Access and 'Readiness'

"It was all hands on deck," recalls Dr. Rising, an emergency medicine physician and clinical researcher.

An onslaught of patients sickened by the coronavirus was quickly filling up the clinic; meanwhile those with chronic illnesses and other health concerns still needed care. Fortunately, Jefferson Health had been honing its telehealth platform — JeffConnect — since its launch in 2015, and was poised to expand the service.

"Our call volumes tripled overnight," says Anna Marie Chang, MD, an emergency medicine physician working closely with Dr. Rising, and a core member of the JeffConnect team. "We trained more than a hundred doctors across the enterprise to handle the influx."

Even as telemedicine sky-rocketed during this first wave of the pandemic, there were many patients who didn't have the resources to access it. A glaring spotlight was put on the 'digital divide' that particularly impacts patients of lower socioeconomic and educational status, communities of color, those who are older, or living in rural areas. These were the same communities that were being hit hardest by the pandemic. Without addressing the lack of access, telemedicine could worsen the impact of COVID-19 and existing health disparities.

As part of the Coronavirus Aid, Relief, and Economic Security (CARES) Act, Jefferson Health received funding from the Federal Communications Commission (FCC) (as well as from the Philadelphia Mayor's Fund, TD Bank, and Aetna/CVS) to expand their telehealth-related services. Dr. Rising led the application of the CARES funds which were used to purchase iPads and remote monitoring devices to give to patients who didn't have devices at home. But she and her colleagues soon realized there was another challenge.

"Enabling access to devices didn't mean patients were automatically going to make a telehealth appointment the next day," she explains. "It was clear that many patients just weren't comfortable using telehealth, and we needed to find out why."

Dr. Rising started delving into research published on 'the digital divide' in an effort to guide solutions. She came across the term 'digital readiness' — it was a concept that encompassed the complexities surrounding the use of technology and addressed three main questions:

1. Does a person have access to a device/technology, and the skills or knowledge to use it?

2. Does a person accept the technology as a relevant tool for its designated purpose, e.g. online learning or telemedicine?

3. Does a person trust the technology?

These questions provided a framework for understanding nuances that drive patient behavior, like those Chelsea observed in her parents.

> ## "It's about a mind shift that we as healthcare providers have to help people get through."
> ### *Dr. Rising*

"For so long we've thought about the digital divide mainly in terms of access and knowledge," says Dr. Rising. "This concept of 'readiness' shows us that it's more about a mind shift that we as healthcare providers have to help people get through."

Bridging the Digital Divide

It was apparent that patients were on a spectrum of digital readiness, and the critical next step was to identify those who were less 'digitally ready.' At the Sidney Kimmel Cancer Center — Jefferson Health, physicians were alarmed to realize that this was a significant portion of their patient population.

"Cancer patients tend to be older, and many belong to racial and ethnic minorities, a reflection of complex health disparities," explains Brooke Worster, MD, who specializes in palliative medicine for cancer patients. "Many of these patients were less likely to have access to or use technology in their everyday life, let alone in their cancer care. If we didn't reach out to them, they could be in danger of not getting vital treatment, screening and follow-up care."

With astonishing speed, Dr. Worster and colleagues mobilized resources and staff, which included social workers, research assistants, physicians and nurses, and by late March 2020, they had created the Telehealth Taskforce. It was designed to provide one-on-one assistance to cancer patients with smartphone set-up and delivery, creation of email accounts and online health portals, testing device video and audio, and real-time help during telehealth visits. Each patient had different needs, and assistance was tailored accordingly. Because of COVID restrictions, all this had to be done over the phone or a video call.

The Telehealth Taskforce provided a model for how to triage telehealth assistance, and Dr. Rising saw an opportunity to expand it to other areas of care. She collaborated with Rosemary Frasso, PhD from Population Health, and others, to create the Digital Onboarding Taskforce in September 2020. They recruited public health and medical students who were eager to get hands-on patient-care experience and offer help during a time of crisis. They provided similar one-on-one, virtual assistance as the Telehealth Taskforce. Together, the two initiatives helped more than 2,000 Jefferson Health patients overcome barriers to using telemedicine, including access, knowledge and acceptance.

But, Dr. Rising says, there was one component of 'digital readiness' that still lingered— the multi-layered issue of trust.

Mistrust in Health Care Affects 'Digital Readiness'

Before the pandemic, Black patients used telehealth services less often than

white patients, but that gap widened substantially as telehealth became the primary way to see a healthcare provider. In the early months of the pandemic, Dr. Rising and geriatric psychiatrist Barry Rovner, MD, led a group of researchers to assess what could be contributing to this disparity. They surveyed 162 Black patients with diabetes and found that despite the fact that over 90% of the participants had the technology and capability to access telehealth, only 39% had a telehealth visit during the pandemic. They looked at contributing factors like age, gender, years of education, cognitive ability—and it had nothing to with any of those. It all came down to trust.

"Participants had less trust in doctors' ability to diagnose and treat their symptoms using telehealth," explains Dr. Rovner. "There was also the fear of discrimination, and that doctors don't always have their best interests at heart."

These fears are justified, given the long history of abuse towards communities of color in the U.S. medical system — from the infamous Tuskegee Study to Henrietta Lacks, a Black woman whose cells were taken from her body without her consent and widely used in medical research. The mistrust is also rooted in a lack of representation in the medical field — less than 6% of doctors in America are Hispanic, only 5% are Black, and less than 1% are Native American. For patients like Chelsea Torres and her parents, it's a struggle to find culturally competent care.

"It shows up in basic things — a doctor might tell me to eat more vegetables and presume I understand that to mean leafy greens, cruciferous vegetables, etc.," explains Chelsea. "But, in Latino culture, vegetables are beans, legumes, plantains, and others that I only know the names for in Spanish. There's a disconnect."

Chelsea also describes how her parents grew up with a very different healthcare culture in the Dominican Republic — home remedies were a staple, like soothing teas made from herbs in the garden; if there was a health concern they would often call the family doctor, or even get advice from the local pharmacist; medications were cheap and didn't require an appointment to refill.

"If you're used to low-cost, low-effort health care, it can be really overwhelming to navigate the U.S. medical system," says Chelsea. "Then there's the added concern about being discriminated against, dismissed or not understood. And now you're being asked to use this new thing called telemedicine? It's just one more barrier. I understand why my parents are apprehensive."

Engaging Communities to Build Trust

It became clear to Dr. Rising that in order for telehealth to be truly inclusive, building trust in under-resourced communities would be instrumental in sustainably leveling the playing field of 'digital readiness.'

"But trust is not something you can build overnight," says Amy Leader, PhD, a key collaborator of Dr. Rising and public health researcher who studies health disparities. "There are deep, systemic, generational issues at play, and it's going to take a lot of work to dismantle them."

"The taskforces reiterated a key tenet of my research — listen to patients," says Dr. Rising. "This is the first step to building trust, and it means adopting a high-touch approach: get into the communities and start conversations."

Community-led organizations are a conduit to those conversations and the lived experience of navigating health care. Esperanza Health Center, a multi-cultural ministry providing holistic health care to the Latino and under-resourced communities of Philadelphia, is one such example. Esperanza has been instrumental in providing access to culturally competent, multi-lingual care all through the pandemic. And their leadership observed similar limitations in telehealth engagement as Dr. Rising did. A natural partnership formed in the winter of 2020, with the eventual goal of developing a toolkit to improve digital readiness in Latino populations in the Greater

Philadelphia area. The toolkit would include educational materials, in readily understandable language and in Spanish, to address telehealth-related barriers specific to this community. Eventually, this 'digital readiness' toolkit will be replicated in other communities; Dr. Rising hopes to do so through an emergent telehealth advisory board that includes partners such as Philadelphia Fight, Philadelphia Chinatown Development Corporation and SEAMAAC (Southeast Asian Mutual Assistance Association Coalition). Together they serve refugee, immigrant, and other under-resourced populations across Philadelphia.

In order to understand the specific drivers of mistrust of telehealth in the Latino community, Dr. Rising and Esperanza leaders are currently conducting interviews and focus groups with community members, led by a trusted liaison. Chelsea Torres is one of them. She had interned at Esperanza three years ago, and had returned to volunteer during the pandemic, providing education about the vaccines and helping schedule appointments. She heard about the project with Jefferson Health and was chosen to be a community research assistant. In this role, she will collect and digest qualitative data from her interviews with the community, which will in turn inform the development of the toolkit. It's a responsibility that she takes very seriously.

"I come from a big family, and many of my loved ones struggle with health conditions that maybe went neglected because they couldn't find culturally competent care," Chelsea says. "As someone they trust, I have an opportunity to help them feel empowered to use resources like telemedicine to take charge of their health."

"It's critical to have Chelsea on our team, and the focus groups are a key element of the process of building relationships with communities that have felt disenfranchised for so long," says Dr. Rising. "As researchers and healthcare providers, we need to demonstrate that we're invested in listening and making changes based on what communities are telling us."

Connecting Efforts for Sustainable Change

Translating the lessons learned into action is what drives the Center of Connected Care, which launched in January 2021 with Dr. Rising at the helm. Behind her is a multidisciplinary team, the core of which is formed by Drs. Worster, Leader and Chang — they bring a range of expertise and perspectives, from social work and population health to nursing, cancer care and emergency medicine. One of their foundational missions is to ensure digital equity across all communities. This means equitable access, comfort, trust and flexibility of care.

"Health care is not 'one-size-fits-all' and there will always be patients who prefer in-person care to telehealth," says Dr. Rising. "But the idea is to give everyone the ability to include telemedicine in their healthcare toolbox, and the confidence to use it when they want to."

The partnership with Esperanza, which is in its nascent stages, is an example of the unique patient-centric approach

the Center will take in addressing digital readiness and their overall goal of tackling health disparities. It reflects a shift in the field, from research *on* the community, to research *with* the community, say Drs. Leader and Rising, whose collaborative and independent work have often included a community or patient-advisory board. "That's where trust comes from, when it feels like you're part of the solution," says Dr. Leader.

The Center will also expand on the lessons learned from the taskforce; one in particular is the need to measure the range of digital readiness in the patient population. Dr. Worster says that if they had identified the least digitally ready patients ahead of time, there would have been a safety net for them when the pandemic hit and forced the shift to telemedicine. The Center hopes to provide that by integrating a 'digital readiness' screening questionnaire into patient care. The idea would be to administer it when patients first interact with the health system, whether through telemedicine or during an in-person visit. It would then be administered annually thereafter to capture how digital readiness may change with ever-evolving technology, says Dr. Chang. The data collected from these assessments will help design evidence-based and targeted interventions.

For example, if trust is the biggest barrier for a specific patient group, then an intervention would be centered on having educational and information-gathering sessions with trusted and culturally competent liaisons. Similarly, in an upcoming grant, Dr. Leader and Dr. Rising propose embedding a team of specially-trained patient navigators dedicated to telehealth into clinical settings to guide patients who are less comfortable with technology.

The team has a long road ahead of them, but Dr. Rising is excited about convincing funders and policy makers to invest in digital equity. A sign of their progress already — they will host a national conference funded by PCORI (the Patient Centered Outcomes Research Institute) in spring 2022, bringing together diverse stakeholders from across the country who have been tackling digital readiness in their own communities to determine best practices, understand knowledge gaps and develop new research partnerships.

"It took a pandemic to bring telemedicine and digital inequities into razor-sharp focus," says Dr. Rising. "And telemedicine is here to stay, so it's up to us to ensure that it becomes a means of decreasing health disparities, and not increasing them." ■