White Paper

A qualitative study of barriers and potential interventions for healthcare accessibility among people with disabilities during the COVID-19 pandemic in a majority-Hispanic U.S. city

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A Qualitative Study of Barriers and Potential Interventions for Healthcare Accessibility among People with Disabilities during the COVID-19 Pandemic in a majority-Hispanic U.S. City

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Abstract

Background:

In Texas, 1 in 4 individuals live with at least one functional disability. Health disparities and accessibility to needed healthcare and social services for this population are a public health concern.

Objective:

The primary aim of the current study was to broadly understand the experiences of People with Disabilities (PWD) in Texas and their access to vaccination. Our secondary goal was identifying best practices in disseminating critical public health information and resources to this vulnerable population.

Methods:

As part of a Coronavirus Disease-2019 (COVID-19) vaccine education and outreach project, a convenience sample of eleven community partners engaged was selected for qualitative semi-structured interviews to understand facilitators and barriers that PWD face in obtaining healthcare services during the COVID-19 pandemic. Interviews were transcribed and analyzed using rapid assessment procedures.

Results:

The results indicated that PWD experienced additional burdens in obtaining equitable healthcare treatment and information during the COVID-19 pandemic. Three general themes were identified through the analysis of the qualitative interviews: environmental barriers, disparities in healthcare access, and potential interventions.

Conclusions:

The findings suggest there are challenges with healthcare accessibility among PWDs concerning vaccination, testing, and treatment during infectious disease outbreaks, such as COVID-19. The resources created for targeting the awareness of the community regarding vaccines and treatment for COVID-19 often were difficult to access for PWD, which may have further deepened health disparities for disability communities. Including PWDs in discussions on effectively meeting their needs, along with educating healthcare providers on effective communication methods for PWDs and providing them with communication resources are fundamental steps that public health professionals must consider in preparing for future outbreaks and pandemics.

Introduction

The 2021 American Community Survey (ACS) reported that over 3.5 million Texans have at least one disability.[1] This translates to an estimated 1 in 4 adults in the State of Texas who live with a disability.[2] The World Health Organization defines disability as "an interaction between a person's functional impairments and the physical and social environment."[3] The term "Persons with Disabilities" (PWDs) represents those who experience visible or non-visible disabilities.[4] In the U.S., these functional impairments are commonly categorized into six types: mobility, cognition, blindness, deafness, independent living, and self-care.[5] A report on disabilities among working-age adults, based on data from the National Health Interview Survey from 2011 – 2014, noted that up to 40% of persons in this population have more than one functional disability.[5]

People with disabilities (PWDs) in Texas are more likely to experience health disparities.[2] For example, these adults are twice as likely to develop heart disease and/or depression.[2] People with disabilities are also more likely to have chronic health issues.[6,7] Additionally, socioeconomic disparities are prevalent among adults with disabilities, including a greater likelihood of living in poverty, being unemployed, and not having a high school diploma.[5] One in five Texans with a disability live an impoverished lifestyle and lack access to adequate healthcare.[1] One study found that those with no disability (76.1%) held private insurance more often than those with physical disabilities (57.4%) and those with cognitive limitations (44.8%).[7]

On March 13, 2020, Texas declared a public health emergency in the face of the COVID-19 pandemic.[8] This declaration activated the public health structure to support community-based mitigation strategies such as social distancing and isolation, mask-wearing, and increased sanitation measures (hand washing and cleaning). With the progression of the pandemic, testing and vaccination were added to the toolkit of strategies for combating this global health threat at a local level.

The World Health Organization reports that "Persons with disabilities die earlier, have poorer health, and experience more limitations in everyday functioning than others."[9] The COVID-19 pandemic highlighted and exasperated already entrenched health disparities and put PWDs at risk for increased marginalization in health care during this public health crisis.[10,11] Emerging evidence suggests that COVID-19 impacted PWDs with higher morbidity and mortality rates compared to non-disabled populations. A recent study by Croft and Fraser analyzed the impact of barriers and facilitators among PWDs during the COVID-19 pandemic. This research identified subcategories of barriers towards PWDs, including access to information, ease of communication, financial impacts, mental health impacts, access to essential services, physical safety, educational challenges, and changes to care and rehabilitation.[12]

As part of the diverse awareness and educational programs that were enacted to address these barriers, in 2021, the UTHealth School of Public Health (UTSPH) was awarded a COVID-19 Vaccine Education and Outreach grant sponsored by Texas A&M University and the Texas Department of State Health Services to bolster vaccination

efforts within vulnerable communities. The UTSPH project focused on recruiting and training volunteers in the San Antonio region as "Ask Me" Ambassadors, whose role was to share personal stories and science-backed information in zip codes with low vaccine acceptance rates. Our goal was to identify diverse community members and equip them with the training, tools, and encouragement to share their positive vaccination stories and vaccination resources within their circles of influence, especially among populations with low vaccination rates. A secondary activity included facilitating live vaccination-related training and Q&A sessions for community health workers statewide. During this work, the project team recorded anecdotal evidence of barriers to vaccination and other types of healthcare among individuals with disabilities.

For this study, the primary aim was to interview service providers working with PWDs to broadly understand the experiences of this population in Texas during the COVID-19 pandemic, including their access to vaccination. Our secondary aims were to (1) identify effective practices in disseminating information regarding healthcare and vaccination accessibility during the pandemic and (2) identify promising interventions to improve healthcare accessibility during public health emergencies (e.g., infectious disease outbreaks). Our qualitative study assesses the gaps in health care and vaccine accessibility for PWDs during the COVID-19 pandemic in Texas.

Methods

This study was part of a quality improvement initiative based on a funded service outreach project. An IRB requirement was exempted as this was an evaluation of a

service-based activity and posed no more than minimal risk to the respondents. UTSPH team members engaged with community members, organizational stakeholders, frontline public health workers (e.g., community health workers), and other grantees and identified stories of disparities in vaccine access among children and adults with disabilities, as well as opportunities to make vaccine information and services more inclusive.

Key informant interviews were selected as the most appropriate method to solicit and record the perspectives of the community partners engaged in assisting and working with PWDs. We conducted semi-structured interviews from a convenience sample of 11 partners from six organizations (Table 1) representing non-profits and public health agencies that met the inclusion criteria of working closely with PWDs in Texas. A literature review was conducted to develop a standardized question sheet to avoid any potential discrepancies. Our focus questions were to assess the accessibility of health care services for PWDs in general and during unprecedented circumstances such as a pandemic. The two main questions being: (1) What was the experience of PWDs whom you serve in relation to vaccine and healthcare access during the COVID-19 pandemic? and (2) What kind of public health emergency preparedness and response activities does your organization promote, if any, with PWDs?

The interviewees were invited for interviews by email. A team of at least two project researchers conducted interviews on the Zoom platform lasting approximately 60 minutes with ample time to explore the topic in detail. These were transcribed using an

AI transcription application (Otto). Each interview transcript was analyzed using a Rapid

Assessment Procedures (RAP) method, which allows for rapid content analysis, a team

approach to the research process, and an iterative cycle of data collection and

analysis.[13] Reviewers independently assessed and generated a codebook for themes

and subthemes regarding barriers to vaccine access and ways to improve accessibility.

Results

The results indicate that PWDs experienced additional burdens in obtaining equitable

healthcare treatment and information during the COVID-19 pandemic. Table 1 highlights

the interviewees' roles associated with PWDs and the type of organizations they were

associated with.

Three major themes were identified through the qualitative interviews conducted during

this study. The themes identified were environmental barriers, gaps in healthcare

access, and potential interventions, as seen in Tables 2 and 3.

Environmental Barriers:

This theme was defined in the codebook as "Factors in a person's environment that,

through their absence or presence, limit functioning and create disability. The

highlighted barriers included a physical environment that is not accessible, lack of

relevant assistive technology (assistive, adaptive, and rehabilitative devices), negative

attitudes of people towards disability, services, systems, and policies that are either

nonexistent or that hinder the involvement of all people with a health condition in all

areas of life."[14]

Within this theme, the salient subthemes of Language, Information, Access, and Transportation barriers emerged. From a hearing-impaired person, "I do not read and write your language… that information isn't clearly right there when I get there, I can't navigate your website to get to it." This excerpt from our study illustrates how these barriers present in real life for PWDs. The barriers are often intertwined with the inability to communicate in an established language like American Sign Language (ASL), which led to difficulties in obtaining information. Situations like these, where individuals must communicate in their non-primary language, lead to less-than-ideal communication results. A previous study by McEwen et al. estimated that the medical communication skills of deaf individuals may be similar to those of third to fifth-graders when communication is only provided in English.[15]

Disparities in Healthcare Access

The theme of Disparities in Healthcare was defined in the codebook as "preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations"[16] and by the Institute of Medicine, which suggests that "health disparities are racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention."[17]

Within this theme, the subthemes of Disability Type, Lack of Social Support, and Lack of Demographic Information emerged. From a translation service provider: "…So even today, did you know the national stats that only that 9 out of 10 parents with deaf or deaf-blind kids never learned to sign?" Literature suggests that there are at most 40% of

parents who know American Sign Language.[18] This excerpt from our study demonstrates the lack of social support PWDs face.

Potential Interventions for Response:

During the interviews, respondents emphasized and identified Potential Interventions to improve response for PWDs during emergent situations. This included the subthemes of Disability Inclusion, Educating The Community, Educating Healthcare Providers, Addressing Misinformation, Improving Access and Accessibility, and Implementing Targeted Programs for Individuals with Disabilities. An interviewee pointed out, "It's like they [PWDs] need to have a separate preparedness plan. You know, our regular preparedness plan did not fit them."

The significance of addressing misinformation was discussed repeatedly, as PWDs are accustomed to advocating for themselves and seeking information to improve their lives. The rapid dissemination of information nowadays through social media from unreliable sources adds the burden of fact-checking to the consumer before it gets shared. A participant noted this: "If you don't know that information is out there and in an accessible format no matter how ridiculous it is…they share the same misinformation…Someone told them the president on TV said that ....COVID Finish done." Thereby giving the false impression that the pandemic was over.

It was also brought to attention that educating healthcare providers on the needs of PWDs and providing tools to improve access to healthcare will assist in improving equity to this population. Ensuring that individuals with disabilities are included and able to get to events and places where they wish to be is perhaps one of the most essential

steps that can be taken. A quote from an interviewee highlighted this need: "Providing safe spaces, or disability-friendly spaces is really important." To hear from PWDs, they must be able to present without incurring excessive burdens to use their voice.

Suggestions from the interviewees noted the importance of including PWDs in efforts related to alleviating health inequity for PWDs. From the interviews, "We have to educate the people providing the resources..." and "Yah…we do want to be a part of this, you know, problem solving." And "I learned so much from the disability community." Providing educational workshops, disaster preparedness programs, inclusive flyers, advertisements, and websites with inclusion of PWDs are tangible steps that our study participants suggested as ways to make healthcare more accessible for PWDs as highlighted by a key informant, "I think developing these resources for specific populations is really important."

Table 4 includes significant supporting quotes that are notable to mention as they highlight the recurring discussion that all interviews deciphered in accessibility issues and solutions.

Discussion

Through a literature review and a series of key informant interviews, our rapid assessment underscored a growing consensus that the current constructs of our public health system are not adequately prepared to address the needs of PWDs during a disease outbreak. It was identified that during the COVID-19 pandemic, PWDs faced compound challenges of existing health disparities and inadequate information and healthcare access.

Literature suggests that PWDs compensate for the lack of accessibility literacy that healthcare professionals often have regarding disabilities and that this hampers effective discussions about fundamental health requirements of PWDs. Our analysis suggests that this burden may be alleviated by training health providers about accessibility and providing them with educational tools and resources, as reported by other authors.[6] One of the interviewees who provides disability-friendly healthcare training and toolkits shared, "Our education program...walks them through the different types of disabilities...some of the tools and resources and how they're utilized." Our study further suggests specific training for healthcare providers targeting PWDs' needs during public health emergencies, such as a pandemic. It is also important to note that during these emergent situations, being prepared with proper training will save time and energy while ultimately resulting in more positive health outcomes. In our study, one interviewee reported that educating community members would "create safe and trusted spaces that people with disabilities are actually willing to go to and participate."

Evidence highlighted that resources created for targeting community awareness regarding vaccines and treatment for COVID-19 were difficult to access by PWDs.[19] The lived experiences captured in our interviews reverberate with similar findings of PWDs encountering additional barriers when seeking out COVID-19 vaccinations and accurate information. The major themes identified inequitable healthcare accessibility for PWDs, lack of social support, and barriers to healthcare. It is imperative for the healthcare system to be aware of this dynamic to ensure equitable strategies to support PWDs.

Relevant interventions emerging from this study comprised of educating community members, training healthcare providers, and including PWDs in the development of

solutions. Additionally, creating inclusive flyers and websites can be an essential step in improving PWDs' accessibility. Braille on flyers or having alternative text and videos on websites that describe services are a few examples mentioned by interviewees. New and up-to-date communication styles must be enabled in emergencies to improve access to care, disseminate medical information, and provide public health updates at points of care.[20] A recent qualitative study that interviewed 3 PWDs in Texas concluded that young PWDs suffered extensively during the Pandemic.[21]

There were a few limitations in the design of this study. As expected, we collected a small sample size despite a 67% participation rate. However, we found some common themes in the survey data that offer compelling insights. While an AI application transcribed the interviews, the authors suggest that future studies might benefit from recording them directly to capture any nuances missed by the transcription process.

To understand the full extent of the negative impact of the COVID-19 pandemic on PWDs and potential interventions, further studies and research must occur.[22] Therefore, we conclude that the cycle of health inequity impacting PWDs may continue until more dedicated studies and attention are directed toward this vulnerable population.

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Table 1. List of Interviewees

Name	Type of organization	Position	Location
interviewee 1	State health agency	Office of Border Public Health Program coordinator.	South Texas
interviewee 2	State health agency	Office of Border Public Health prevention specialist	South Texas
interviewee 3	Non-profit	Founder and executive director of an organization dedicated to assisting people with disabilities and educating health professionals on how to provide equitable care to PWDs	Central Texas
interviewee 4	Protection and advocacy agency	A lawyer who assists PWDs with legal services and fighting for equitable opportunities.	Southeast Texas
interviewee 5	Non-profit	Founder and CEO of organization that assists deaf and blind people with communication and emergency alerts.	Nationally, based in Texas
interviewee 6	Non-profit	Director of Emergency Services and president of organization that assist deaf and blind people with communication and emergency alerts.	Nationally

Table 2. Themes and sub-themes Identified through Qualitative Analysis of interviews with example quotes.

Themes	Sub-themes	Example Quote
Barriers	Language barriers	"sign language has no roots in English... it has no writing system. So here you are, and you're gonna tell all of this population. Go to the website and register...that'd be like me telling you it's in Swahili go register."
	Information barriers	'... sit down for 15 minutes to see how you feel... In San Antonio alone. Three people who are deaf died from complications because no one could say you need to sit and wait."
	Access barriers	"what people went through with the pandemic was just another version of what they go through every day... now that the pandemic is over… people can go back to the regular ways of doing things, which already kind of like sucked, right. So, we're back to our general suckiness"
	Transportation barriers	"Our cases were those that didn't have transportation or were essentially homebound. [They] couldn't get to vaccinations"
Gaps in healthcare	Based on disability type	"I think physical accessibility is... the first thing we think about oh, we look at ... But then, but then you need to move on right to what are other disabilities and what do we need to be aware? " "But education and awareness about the disability community is lacking in general"
	Lack of social support	"And they don't have anything that's inclusive of the disability come in and even vulnerable populations in general, right when you're talking about LEP, immigrants, homeless, I mean, all of those it fits under that umbrella."
	Lack of Demographic information	"...even if you look at Vaccine Information [data], it's there's not disability specific stuff. It's race, gender...but in order to truly check disparities, you've got to have the data to start with, right. So that's one of the things we are trying to have..."

Table 3. Themes and sub-themes Identified through Qualitative Analysis of interviews with example quotes.

Theme	Sub-themes	Example Quote
Potential Interventions	Disability inclusion	"everything in ASL and simple language and information that was designed with people with disabilities in mind from social stories ... included in our kit communication boards"
	Educating the community	"we have to educate the people providing the resources if we're going to create safe and trusted spaces that people with disabilities are actually willing to go and participate"
	Educating health providers	"We are targeting the pharmacists and the lead physicians. Aiming to develop an online training... and once a pharmacy or clinic gets to the 70% completion rate. Then they will be recognized as a disability-friendly location on our website"
	Addressing misinformation	"I think developing these resources for specific populations is really important."
	Improving access	"Yeah. But we do want to be part of this, you know, problem solving. solution. And it's about bringing the right people to the table. I don't have all the answers... But I can identify when we have a gap or bring in the right people like I learned so much from the disability community, you know..."
	Improving accessibility	"while we serve the health department's but because our interpreters are medically certified to be sure that we don't sign something wrong."
	Targeted programs/ practices for people with disabilities	"We needed an emergency preparedness sheet for individuals and family right that was inclusive of the disability community needs."

Table 4: Supporting Quotes Identified through Qualitative Analysis of interviews

Themes	Quotes
Barrier to Access	"When their internet has problems,...And what do you do? You call whoever you have your internet service with...they come out to your house and do whatever. Imagine you can't talk to them and they don't know what you're saying. And they write you a note and it loaded up and then they get ticked off and leave and it never gets fixed."
Disability Inclusion as Solution	"And so, of course, everything in ASL and simple language and information that was designed with people with disabilities in mind from social stories and so on and so forth"
Educating Community as Solution	"in the community.. we hope to bring to the people that we've been working with that have the same inexperience as we do with working with populations with disabilities"
Addressing Misinformation as Solution	"we're working on ..educating the community on how to plan and how to ask the right questions. But then the misinformation …with COVID…how do you develop a curriculum to address that"
Improving Access as Solution	"it's like they [PWD] need to have a separate preparedness plan. You know, our regular preparedness plan did not fit them."
Targeted Programs/ Practices for People with Disabilities as Solution	"So we clip it off, put our QR code there. And now everything that's on there is accessible...But all the information that you want to share, making it accessible, whether it's on your website, or it's in your flyers"