Key Stakeholder Perspectives of Community Engagement Efforts and the Impact of the Covid-19 Pandemic

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Abstract

Introduction: The COVID-19 pandemic has disproportionally affected historically marginalized populations and their access to resources and healthcare. In times of crisis, authentic community engagement is more important than ever. This study was Phase I of a larger 3-phase study to conduct timely community-engaged research with community members to understand the disproportionate impact of COVID-19 on historically underserved communities. The objective of this work was to conduct key informant (KI) interviews (1) to understand community organizations perspectives about the role that large academic health centers play as they interface with community organizations to support their work, (2) to leverage KI's expertise to identify needs and assets within the community, and (3) to inform both Phase 2 (focus group qualitative research) and Phase 3 (survey) of the broader study. Methods: A total of 24 key informants were identified through purposeful sampling and one-on-one semi-structured interviews were conducted across 4 states using video conferencing. Results: Barriers to access and lack of transparency were highlighted as major issues requiring reform-in particular, aggressive billing practices and insurance barriers exacerbated local distrust of medical institutions. KIs recognized the health institution's support for testing and vaccination during the COVID-19 pandemic, but noted other significant gaps in care, especially regarding mental health support. Although communication with the health institution was consistent for some KIs, others experienced unsustained communication efforts that hindered cooperation and relationship building. Conclusions: Leaders in the community as key stakeholders can provide unique insights into the challenges and potential solutions required to promote health equity, and foster understanding between local communities and healthcare institutions.

Keywords

community engagement, key informants, qualitative data, COVID-19, access to care

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Introduction

The COVID-19 pandemic has disproportionally affected historically marginalized populations and their access to healthcare and other resources. Black and Hispanic communities experience higher rates of coronavirus infections, hospitalizations, and mortality compared to White communities.^{1,2} These findings highlight the need for healthcare reform and attention to health disparities.^{3,4}

In many of these communities, medical anchor institutions have begun taking initiatives to address the needs of under-resourced populations.⁵ These institutions serve a vital role in communities, mobilizing economic resources to support local community-based organizations and to promote health.⁶⁻⁸ There is increasing emphasis on the role of large academic health systems in supporting local communities and as potential "anchor institutions."⁵⁻⁸

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Community engaged research (CEnR) is defined by the Centers for Disease Control and Prevention as "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the wellbeing of those people."⁹ By understanding stakeholder and community needs, CEnR approaches can influence public health initiatives and address health disparities.^{7,8,10,11}

In times of crisis such as the global COVID-19 pandemic, authentic community engagement is more important than ever to build trust in healthcare and public health organizations and highlight issues of food insecurity, education, and economic opportunities.^{7,8,10,11} Community engagement aids researchers in formulating culturally sensitive interventions to support the needs of underserved populations.¹² This approach helps community organizations improve the effectiveness of their programs, which can in turn improve their ability to empower community interests.¹³

Consulting key informants (KIs), community experts that hold formal positions and have special or relevant knowledge, is crucial to formulating a comprehensive view of a community's health needs.¹⁴ Conducting KI interviews helps glean insight into the intricate networks of these communities, including the experiences and needs of people from disenfranchised and underserved groups.¹⁵

This study was part of a larger 3-phase research program developed to conduct timely community-engaged research with community members in order to understand the disproportionate impact of COVID-19 on historically underserved communities. The objective of this phase of the study was to conduct KI interviews (1) to understand community organizations' perspectives about the role that large academic health centers can play as they interface with community organizations to support their work, (2) to leverage KI's expertise to identify needs and assets within the community, and (3) to inform Phase 2 (focus group) and Phase 3 (survey) of the research program.

Methods

Study Setting and Design

The Phase 1 of our work described in detail in this paper was part of a mixed methods study. In Phase 1, we used purposive sampling to identify key informants from multiple stakeholder groups and conducted semi-structured interviews. In Phase 2, we held focus groups with community members from historically marginalized demographics. In Phase 3, we developed a survey using validated scales and distributed it to diverse communities residing in the geographic areas of our healthcare system across 4 states. Phase 1 of the study were approved as minimal risk by the Mayo Clinic IRB (21-001802). We conducted Phase 1 between March and July of 2021 across the Mayo Clinic Health System (MCHS) which includes the catchment areas of the 3 academic medical centers and the health system. Mayo Clinic is a health care organization with a wide geographic reach, with hospitals in Scottsdale, Arizona; Jacksonville, Florida; Rochester, Minnesota; and a Health System spread throughout Minnesota and Wisconsin.

Phase 1: Key Informant (KI) Interviews

Participants and recruitment. Our study team used purposive sampling to identify key informants (KI) from multiple community stakeholder groups that included county public health officials, safety net medical providers, community leaders, non-profit organization executives and staff, and health system leadership. We connected with stakeholders via email or phone to outline the nature of the study and participation requirements. All consent forms were automatically emailed to those who agreed to participate and completed via *DocuSign (DocuSign, San Francisco, CA)* prior to the interview.

The broader study team developed the interview guide which contained questions that explored the mission of the organization within which the KI was working, communities the organization served, health challenges facing those communities, current efforts to address the needs and assets, and research needed to amplify current work (Appendix 1). Other included questions asked about the specific effect of COVID-19 in those communities, how services were modified to meet needs, and suggestions for efforts and research to support and prepare communities for future similar events, as well as the organization's relationship with MCHS and current collaborative initiatives.

Data collection. We scheduled online video conferencing interviews for up to 60 min. Study team members (AB, KC) conducted one-on-one, semi-structured interviews. We did not offer remuneration.

Qualitative Analysis

We recorded all KI interviews, and the audio recordings were transcribed verbatim and de-identified prior to analysis. Interview data were organized and analyzed using the Framework analytic approach.¹⁶ Trained coders (AB, KC, TC) collaborated on each phase of analysis, from indexing to exemplar (quote) retrieval; (KC, LH, AB). Coding was guided deductively by the interview guide and left open to inductive findings as they arose during the coding process.

Results

KI Interviews

We conducted 24 KI interviews. Demographic, geographic, and organizational sector characteristics are outlined in Table 1.

Table I. Demographics.

Number	Sex and race/ethnicity	Organizational sector	State/County
I	Female/White	Insurance marketplace	MN/Olmsted
2	Male/Asian	Non-profit	
3	Female/Hispanic	Non-profit	
4	Female/White	Non-profit Food shelf	
5	Female/White	Non-profit health service	MN/Goodhue
6	Female/Hispanic	Non-profit	
7	Female/White	Chamber of commerce (501c6)	WI/La Crosse
8	Male/White	local politician	
9	Male/White	Non-profit	
10	Male/White	Non-profit/University	
11	Female/White	Chamber of commerce(501c6)	MN/Mower
12	Female/Black	Faith-based	AZ/Maricopa
13	Female/Black	Non-profit	
14	Female/White	Research	
15	Female/Hispanic	Non-profit	
16	Female/Black	Faith-based	
17	Female/Hispanic	County Health Dept.	
18	Male/Hispanic	Non-profit	FL/Duval
19	Male/White	University	
20	Female/White	Non-profit	
21	Female/White	Non-profit	
22	Female/Black	Entrepreneur	
23	Female/Black	County Health Dept.	
24	Female/Black	Non-profit	

MCHS's COVID-19 pandemic response was met with both negative and positive feedback. Common themes are provided in Table 2.

Negative Perceptions of MCHS Pandemic Response

Information dissemination and lack of public education. Underresourced communities struggled to stay informed about COVID-19 prevention methods. KIs wished that COVID-19 research was better communicated to the public. They emphasized relaying published scientific findings to lay audiences to promote public education.

Unfair and inaccessible testing and vaccine roll-out strategy. Some KIs noted unfair vaccine rollout decisions by MCHS. They felt that rollout priorities were inequitable and frontline non-profit community organization workers were neglected in this process.

Positive Perceptions of MCHS Pandemic Response

Outreach and education. Other KIs found MCHS's presence to be a "unifying force" and "community focused," addressing the community's needs and providing education in times of uncertainty.

Funding and infrastructure. Many also reported that MCHS was instrumental in supporting and setting up testing and vaccination efforts in local underserved areas. MCHS provided infrastructure and funding necessary to establish COVID-19 related resources for prevention of infection.

Accessible relationships for getting COVID-19 advice. Many KIs felt that they had a strong, accessible relationship with MCHS throughout the pandemic and in some cases the collaborative work conducted during the pandemic had strengthened ties with MCHS and increased awareness of available resources and organizations. Some KIs cited the ability to directly reach MCHS experts as essential during decision making about safe programming in their organizations.

Overall Negative Perceptions of MCHS

Perceived lack of access. Key informants emphasized community distrust and intimidation about seeking care at MCHS. Organizations as well as individuals were skeptical of collaborating or receiving care at MCHS due to the perception that MCHS was too exclusive. KIs illustrate that many community members "have an image of Mayo that it's just not for everybody."

Insurance barriers. Underserved communities did not perceive MCHS as a viable resource due to financial barriers and insurance.

Table 2. Themes.

COVID pandemic impact negative

Information dissemination and public education lacking

There is a need to educate the public and translate current research for lay audiences to inform their health decisions.

Unfair and inaccessible testing and vaccine roll-out strategy

The rollout strategy for the COVID-19 vaccines was perceived to be unfair. Community frontline workers were not prioritized. Testing was inaccessible and impractical at times.

COVID pandemic impact positive

Outreach and Education

COVID catalyzed stronger relationships and partnerships through improved mutual awareness of community organizations.

Infrastructure and Resources

Many local organizations received support and funding from MCHS to support COVID-19 testing efforts. MCHS provided the necessary infrastructure and support to establish testing sites in collaboration with the community.

Accessible Relationships for getting COVID-19 advice Relationships between MCHS and community leaders helped inform decision making during COVID-19 pandemic.

General comments negative

Perceived Lack of Access

MCHS was perceived as elite and exclusive and inaccessible institution among local communities.

Insurance Barriers

Financial burdens of upfront payments and insurance deter the local community from seeking and obtaining medical care. "I think the entire academic community, and that includes health and medical centers, have not been good, at the translation of academic information to the general public. . . How do we get the messages out there? How do we use evidence-based strategies? How do we disseminate that, even to other people in research and academic institutions, other than by publishing in a journal?" IV14

"I do think . . . the vaccine rollout could have been better as far as equity and who was getting them. I'm just gonna say that the nonprofits were pissed when we heard about Mayo office workers getting vaccines before our front-line people. I know that Mayo Clinic says they were following CDC and state health guidelines, but it felt pretty unfair when our client facing staff and our drivers could not get a vaccine, but Mayo Clinic IT people were getting them." IV4 "Initially, it was a little challenging for the population to get their COVID testing done at Mayo. . . there wasn't anyone who could communicate with them in Spanish. That was a little challenging. Then even just to try to keep people safe and separated, their process was you set up your appointment online or over the phone with someone, and then our interpreters would try to call and help them, and then they were told 'You have to be in the same room'—the interpreter and the patient have to be in the same room as someone who thinks they have COVID" IV5

On the COVID community team: "What we have experienced with the team is a coming together of members throughout the community from all organizations. Number one, educating us about the disease. Educating us about the whole concept of what this pandemic was all about and the impact that it could have and what we needed to do to prepare ourselves, to keep ourselves safe, and to keep ourselves healthy. . . I thought Mayo Clinic had done a wonderful job. . .I think Mayo Clinic has really been on the forefront. In my opinion they've been out front in guiding the leadership and I would say really coordinating the efforts to educate the community." IV13

"I just had a meeting yesterday with our local health and human service office, Public Health, and they said one thing that's been good about this is—we've really been working with them on vaccine efforts as well as Mayo Clinic, all three of us. It has been so good to work together, and particularly with this higher risk immigrant population. They just realized that there's a whole group of people that they didn't even realize were a part of our community. ..." IV5

"The grants for my church—we had one \$50,000 grant from Mayo that . . .we (used for) COVID testing." IV16

"We did a large scale COVID testing contract with Mayo this year. We don't have those abilities here on our campus, so that was a great opportunity to even build additional relationships with Mayo." IV10

- "What was helpful for us, and I keep coming back to our relationship, obviously, with Mayo, but I had a couple Mayo members on speed dial. That's who I went to when I had to ask a question about safety. Should we be open? Should we be offering this athletic program? What should we be requiring for visitors or parents?" IV9
- "I don't know if that's a misconception, but when people think of Mayo Clinic, they think of this top echelon type of medical facility. You need money or good insurance to go there." IV12
- "The biggest issue we have found in the past has been the idea that Mayo's for rich people or whatever" IV18
- "Quite honestly, I'm happy to hear that Mayo is interested in our community 'cause, for years, I didn't think Mayo was—I thought they were just physically housed in x, not really having an interest in x" IV22

"That's also one of the big barriers for the community because they're—so many of our patients are so responsible. If they know that they can't afford something, they're not gonna go and have the procedure or whatever done. It's a little scary to say, 'Go have this multi-thousand-dollar visit, and then we'll let you know what your portion of it is." IV5

Table 2. (continued)

ad so many clients who come to me and tell me certain things about Mayo refusing services or ag for certain things before they can have services. That really just taints your view and kind of es it hard to work with Mayo or want to work with Mayo, even though we want to. Just yesterday, I had someone whose mom needed an MRI. Mayo was like, 'No, we have to have a sit of so many thousands of dollars before you can do that.''' IVI <pre>c [collaboration] just kind of gets lost. You would start having a conversation, and then it just n't continue my supervisor feels like Mayo doesn't understand the role that we would play in is of helping their patients or that maybe it's not something that's important, to Mayo.'' IVI a honest, our region is a little bit behind because Mayo has not jumped on board I'm not g that Mayo doesn't want to be involved. We've had conversations, but it hasn't really—it has taken off.'' IV4</pre> table and the door, we can check their insurance. We can make sure it's okay. We can them apply, whatever. We haven't been very successful with that.'' IVI a always been tricky to refer—it used to be very slow, and now they want either up-front tents or people are left with a bill that, well, they're not sure what the bill could be. Is that ect? Yeah. Now you're findin' that even locally is a specialty, let's say rheumatology, and we thave taken their is they have to go to y Mayo for that requires that you pay like \$5,000 ont before they'l even give you that appointment. Obviously, that's a pretty big barrier that our nts can't afford to do that.'' IVS
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supportive in being a participant in the outreach of other organizations. 1913 's outstanding at coming back and sending in people to support us and present. We need the ole to present on health day. All of those hospitals, they rotate where we go, so I year, we'll t at Mayo for health day, the next year'' IV21
k we have a very open line of communication and there's a lot of trust both ways. I think that ionship with community engagement is great." IV14
k conversations, information sharing, I think, would be useful. We often bring people to k before the village board, and I can't really remember the last time there was someone from Mayo Clinic that we brought to speak to us about an informational issue or something as ningful as that" IV3 Id love to collaborate [with Mayo] to be more in contact with providers that have a diverse ground. Then they can help to educate our community in their own language, and also to empower young people, to help to motivate them to explore some of those professional careers." IV6 is the same thing with the COVID shots. You almost had to be a very computer literate, stigative sleuth to figure out where you could go, when you could go, how you made your intment to get a COVID vaccination. It shouldn't've been that hard. There should've been readily able charts. If you have this, you go here. If you have this, you go there. I think the education is ng community wide on what's available." IV21
k we used to a little better job of connecting twice a year usually in a meeting just to share s and areas of potential partnership. It's been a little while since we've done that" IV5
Ve know our kids suffered alone. We did interview some kids and their main concern was tion and mental health and not having their peers. They did not have any access to mental th (support). Their parents were already laid off or furloughed or very stressed having kids at e. Without access to any mental health (support), it was very tough." IV3 ugh everything, I think—when you ask, what else could be done? The whole mental health piece. pandemic] has impacted people in so many different ways. Everybody, whether we actually owledge it, we were all impacted on a mental health level with whatever it was. People were d" IVI I

Collaboration challenges. KIs reported difficulties navigating and sustaining communication and relationships with MCHS. Many KIs believed that MCHS as an institution demonstrated a lack of willingness to meaningfully work with local organizations and this could only be achieved with individuals working beyond the scope of their role.

Lack of transparency. KIs, especially those from safety net sites, discussed the challenges their patients faced when being referred. There is a perceived lack of transparency around billing and referrals for those who need specialized care. These financial barriers to pursing care at MCHS deterred underserved communities from prioritizing their health.

Overall Positive Perceptions of MCHS

Good education and information outreach efforts. In local underserved communities, KIs identified MCHS as a major educational resource and support structure. They illustrated how MCHS plays an active role in the community by bringing speakers to present on various health topics.

Open communication. KIs emphasize that partnerships with MCHS involve bidirectional open communication and trust.

Suggested Improvements

Increase information sharing and education opportunities. Multiple KIs suggested improvements in education of both the community and youth.

Increase connection opportunities. KIs want to increase regular connection opportunities and collaboration efforts with MCHS.

Mental health. Many informants also expressed that access to mental health resources is neglected in underserved populations.

Discussion

This paper describes KI interviews which were conducted as part of a 3-phase mixed methods study assessing the impact of COVID-19 on community health and wellbeing. KIs are local experts and community leaders that play a vital role in addressing the needs of their constituents.^{14,15} They are uniquely positioned to understand local challenges, evaluate how anchor institutions interface at the organizational level, and assess the impact of anchor institutional activities on local health outcomes.^{14,15} As such, KI feedback provides a robust basis for specific, tailored improvements to MCHS's impact in underserved communities that strengthen MCHS's function as an anchor institution. KIs praised MCHS's role in educating the community, recommending that MCHS offer additional educational opportunities and deepen information sharing with local communities. KIs also recognized MCHS's support for testing and vaccination, but noted significant gaps in care, especially regarding mental health. KIs highlighted barriers to access and lack of transparency as major issues requiring reform—in particular, aggressive billing practices and insurance barriers exacerbated local distrust of medical institutions. KIs also identified challenges they faced in collaborating with MCHS—while some enjoyed consistent communication, others experienced poor communication that hindered consistent and ongoing cooperative efforts.

Our study builds on the small but growing literature on the role large medical institutions play in serving local communities during the COVID-19 syndemic-a disastrous confluence of deadly disease, systematic racism, adverse political-economic forces, and institutional violence.¹⁷ We affirm and extend the findings of Leese et al¹⁸ that sustained relationship building, hearing diverse perspectives, and understanding change and uncertainty are crucial to developing a stronger pandemic response. In particular, it is imperative that MCHS and other large health care organizations pursue deeper relationships with local communities to foster trust in medical interventions.^{10,19} They should also deepen their understanding of social determinants of health (SDOH), pre-existing health conditions, and access to care in underserved communities, as these factors lead to worse health outcomes and higher susceptibility to COVID-19 and other diseases.^{20,21} MCHS and other organizations can draw inspiration from the 5-part action plan proposed by Maulik Joshi, of Meritus Health, which aims to combat health inequity and racism by addressing unconscious biases, disparities in care, lack of racial and ethnic diversity in leadership, and adverse SDOH.21,22

Strengths of this study include diverse perspectives from local leaders from organizations within the MCHS community and catchment areas. The insights garnered from KI expertise allow us to implement changes specific to the needs of the community and strengthen MCHS role as an anchor institution.^{23,24} The KI interviews informed the phase 2 and 3 of our study. Our findings will be triangulated by other work in our mixed methods study.

Limitations of the study include the following. While our methodological approach can be replicated in other healthcare systems that wish to conduct robust community engaged research, the positive and negative impressions cited by our KIs may not be the same challenges that community organizations working with other large healthcare systems experience. However, despite issues of generalizability we expect there are likely shared concerns. Furthermore, we acknowledge that some KIs would have had important insights, but due to scheduling difficulties exacerbated by the pandemic, we were unable to interview them. Overall, our findings highlight the need for large academic health centers to act as anchor institutions, especially in turbulent times where COVID-19 has exacerbated vulnerabilities among underserved groups by amplifying problems such as financial instability and lack of access to healthcare.^{12,18,25} Our findings serve as a guide for other large academic centers, informing their outreach efforts and community engagement programs. Based on our findings, future directions include and providing care through additional community engagement and outreach efforts. Further investigation in information dissemination regarding emerging health topics and available health services is needed.

Conclusion

Leaders in the community as key stakeholders can foster understanding and provide insights to inform large academic health centers about approaches to address health and healthcare inequities in the community. Our results highlight the need for community engagement research and the importance of medical anchor institutions in underserved communities during times of crisis. Facilitating partnerships and the exchange of accessible information will help foster trust in the healthcare system.

Appendix I. Interview Guide.

Thank you for joining us. Before we begin can you confirm that you had a chance to review the consent form we sent over and that you are willing to proceed with the interview?

Thank you. With your permission, I will be audio recording our conversation to ensure accuracy. Do I have your permission to turn on the recorder?

Thank you. To start, can you state your role and what you do on a day to day basis?

How would you frame the mission of [organization]?

What communities does [organization] seek to serve?

What are the greatest health challenges facing those communities? What efforts are currently underway to address those challenges? What additional resources or assets would amplify those efforts? What research would help with moving those efforts forward?

Does your organization have any relationship with Mayo Clinic?

Can you tell me why or why not and what you think would facilitate stronger relationships?

I'm going to talk a little about the current COVID pandemic now and how it has affected your community.

How has COVID impacted your organization and the communities it serves?

In addressing the impact of COVID has your organization shifted to any remote services such as phone visits or socially distanced deliveries? Has your organization received any local, state, or Federal support to help with those impacts?

If yes, in what form and how effective was it?

If no, did you apply for or seek any such assistance and why did you not receive it?

How do you think we could better support communities during mass health events such as COVID?

What do you think needs to be done to better prepare our communities for future events?

In the wake of COVID, what research do you think would be helpful in understanding how better to combat these events?

Mayo Clinic is launching a new initiative to drive research in addressing community health needs and disparities. Is that something you think you and/or your organization would be interested in joining?

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