The Role of Non-governmental Organizations in Community-based COVID-19 Education: A Qualitative Study in South Africa and Zambia

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Abstract

Background

Ensuring access to accurate and actionable health information is crucial during the COVID-19 pandemic, especially in low-resource settings. Among marginalized groups, there are disparities in access to information, along with significant mistrust of government sources. Non-governmental organizations (NGOs) involved in community-level health education can play an important role in bridging mistrust and targeting information to reach vulnerable populations. There is a lack of research on the experiences and needs of organizations involved in disseminating health information during the pandemic.

Methods

This study uses a qualitative approach to investigate the current strategies, challenges, and needs of community-based organizations involved in COVID-19 public education. From May to June 2020, we conducted 19 semi-structured interviews with leaders of organizations in South Africa and Zambia. Participants were asked a series of open-ended questions in three domains: 1) the impact of the pandemic on the communities served by the organization, 2) their COVID-19 response, and 3) organization needs and challenges during the pandemic. Interviews were recorded, transcribed, and coded using thematic analysis. Coding and analysis were conducted by four study authors and every interview was independently coded by 2 separate authors to maximize internal validity and consistency.

Results

5 themes relevant to the roles and challenges of locally active NGO's were identified: (1) they intimately understand community needs during the pandemic; (2) they adapt to pandemic constraints to continue supporting vulnerable populations; (3) they play a unique role in educating the public about COVID-19 due to established access and trust within communities; (4) they are able to customize health education and information to address nuanced needs of local communities served; and (5) they need external support to effectively respond to the pandemic.

Conclusions

Overall, our study contributes a deeper understanding of the role of NGOs in providing needed support and customized health education for vulnerable communities during a global public health crisis. To maximize their ability to support their communities, NGO's would benefit from access to educational resources designed to be easily modified, support in navigating technological and safety challenges during the pandemic, and sustainable funding.

Background

While COVID-19 poses a worldwide threat, experts predict that the pandemic will disproportionately impact low- and middle-income countries (LMICs), and evidence is mounting that marginalized groups are at particular risk due not just to the virus itself, but also because of the economic impacts and interruptions to health services [1–5]. Sub-Saharan Africa, with some of the world's greatest infectious disease burden, weakest public health infrastructure, shortage of healthcare workers, and increasing prevalence of high-risk comorbidities, has little margin for treatment and management of COVID-19 patients [6]. Ensuring community access to accurate and actionable health information during COVID-19 will help to reduce the spread of the virus, considering the critical role of personal behaviors such as hand washing and social distancing. Health education programs that aim to improve COVID-19 knowledge have been shown to help maintain both appropriate practices and optimistic attitudes [7].

While governments play a primary role in the dissemination of public health information, marginalized populations, such as women and those with less education, are less likely to receive information from government channels [8]. Mistrust in government, particularly among marginalized groups, has been shown to erode the effectiveness of a variety of health campaigns, including polio eradication efforts, HIV/AIDS prevention, and the containment of the West African Ebola epidemic [9]. Afrobarometer data collected between 2016-18 in 34 countries including South Africa and Zambia show substantial mistrust in government sources and notably higher trust in local leadership including religious and traditional leaders [10]. Specific to the current crisis, a study of media and social media reactions to COVID-19 in South Africa reports a high level of distrust in the government [11].

Non-governmental organizations (NGOs) involved in community-level health education during COVID-19 can play an important role in bridging mistrust and targeting information to better reach vulnerable populations. In the HIV/AIDS epidemic, grassroots organizations have been effective in tailoring sensitive health topics to the needs of diverse groups and in tapping social networks within communities to improve communication [9, 12, 13, 14]. In West Africa, community-level responses were deemed critical in the fight to stem the spread of Ebola [15, 16, 17]. Likewise, local NGOs and civil society have been deemed critical to the remaining efforts to eradicate polio among the hardest-to-reach communities [18, 19].

NGOs may be essential in reaching remote communities with limited access to technology and communication channels (i.e. the internet, social media) where the most up-to-date scientific recommendations are disseminated. According to Afrobarometer data collected in 2016-18, only 20 percent of adults across 34 African countries have access to a smartphone and a computer, and only 43 percent have access to a basic cell phone

[20]. Surveys collected in Kenya in March of 2020 revealed that individuals with lower education were more likely to receive information about COVID-19 from NGOs or public announcements via megaphone [8]. Furthermore, the most up-to-date guidelines may not be accessible in local languages, nor address the glaring resource constraints experienced among more vulnerable populations.

Despite the critical role they play in public health education, there is a lack of research on the experiences and needs frontline organizations involved in disseminating information about COVID-19 in sub-Saharan Africa [7]. Community-based NGOs are experiencing substantial challenges because of the pandemic. Of 1,015 organizations from 44 African nations surveyed in May 2020, 56 percent reported a loss in funding, and 85 percent reported an inability to cope with disruptions caused by COVID-19 [21]. During the ongoing crisis, many organizations may require additional support from the government and international organizations infrastructure to aid the distribution of health information. Additionally, smaller organizations may lack the agency and resources to make their needs heard. To efficiently address the most pressing needs, it is important to better understand the challenges these organizations face and to investigate how they can be better supported to help their communities fight against COVID-19 spread.

This study uses a qualitative approach to investigate the current strategies, challenges, and needs of community-based organizations involved in COVID-19 public education. The insights provided by this study can illuminate the potential to contribute to health education content development and distribution strategies as the pandemic continues to unfold.

Methods

Recruitment

We identified a purposive sample of 9 local non-governmental organizations in South Africa and Zambia with whom the research team was acquainted through prior collaboration within shared global health networks. Criteria for inclusion in the study included (1) active engagement in advocacy and/or delivery of health education and health services at the community level prior to the pandemic and (2) involvement in health education efforts in response to COVID-19 in the communities they serve.

We expanded the sample of organizations using a snowball technique, asking each participating organization to identify other appropriate organizations and by searching the internet for related organizations. Search terms included organizations involved in “community-based health”, “health education”, and “Covid-19 community response”. In total, we reached out to 25 organizations fitting our criteria, of which 19 consented to participate. All participating organizations are non-governmental, except one, which was created by an act of parliament to operate in a semi-autonomous entity under the health ministry.

At each organization, we reached out to directors to obtain permission to be included in our study. We also invited directors to participate in open-ended interviews. If unavailable, directors were asked to appoint another individual within the organization to be interviewed. The inclusion criteria for participation in interviews were adults who 1) were able to speak English, 2) were at least 18 years of age, and 3) held a leadership role in the organization. Of the 19 organizations, 12 are in South Africa, and 7 are in Zambia.

Data Collection

The data for this study were collected through one-on-one in-depth interviews (IDIs) with participants through a phone call or video conferencing. Interviews were conducted by a study author (KK), based in Cape Town, South Africa. To promote open and honest reflection, both interviewer and participants were located in a private space where personal responses would not be heard.

The interviews were semi-structured, with a series of broad open-ended questions in three main domains: 1) the impact of the pandemic on the communities served by the organization; 2) the organization’s COVID-19 response; and 3) the needs and challenges experienced by the organization during the pandemic.

To investigate the impact of the pandemic on communities served, participants were asked about the most pressing concerns in the communities served by the organization, the level of knowledge among beneficiaries about COVID-19 and preventative measures, and their ability to comply with public health recommendations. To learn about organization responses to COVID-19, participants were asked about their organization’s focus prior to the pandemic and how activities had shifted since the start of the pandemic. We also asked about organizations’ methods of sharing COVID-19 information with their community. To understand the needs and challenges faced by the organization, participants were asked what might (or could) help to improve the organization’s response to the pandemic. In addition, we asked about specific challenges related to sharing COVID-19 information and the type of support that could help the organization’s efforts.

Interviews typically lasted 40 to 60 minutes and were audio recorded and transcribed. All personal and organizational information was removed from the recordings and transcripts. The recordings were transcribed by a third-party vendor, Rev.com. All participants provided informed consent and agreed to be audio recorded. Ethics approval for this study was obtained from the Institutional Review Board at Stanford University.

Data Analysis

The data were analyzed in NVivo 12.0, using thematic analysis, a methodology that uses a six-step process to generate themes. Coding was conducted by four study authors (JJ, KA, NJ, KK). Every interview was independently coded by two separate authors to maximize internal validity and coding consistency. First, analysts gained familiarity with the data through reviewing the transcripts. Initial codes were generated, and then codes were organized into potential themes. Themes that persisted across interviews or seemed impactful in the context of the COVID-19 pandemic were considered “key”. The key themes were reviewed and refined until team consensus was reached. The themes that emerged most clearly from the analyses are presented with salient quotations from the interviews.

Results

Participants

A total of 19 organizations located in South Africa and Zambia were included in the study. Participants all held a leadership role in their respective organizations at the time of the interview and were with organizations for a median of 6 years.

Of the 19 organizations included in the study, 13 operate at a national level, and 6 operate regionally within the country. The median age of organizations was 13 years. Organizations reported a range of focal areas, target beneficiaries, and methods of communicating health information to the public (Table 1).

Table 1
Characteristics of participants and their organizations

Characteristic	N (%)
Level of operation	
National	13 (68%)
Regional	6 (32%)
Country of operation	
South Africa	12 (63%)
Zambia	7 (37%)
Participant number of years at organization (median, range)	6 (1, 19)
Less than 2 years	2 (11%)
2-5 years	5 (27%)
6-10 years	6 (32%)
More than 10 years	6 (32%)
Age of organization (median, range)	13 (1,96)
Less than 5 years	2 (11%)
6-10 years	4 (21%)
11-20 years	9 (47%)
More than 20 years	4 (21%)
Primary focus prior to pandemic	
Access to healthcare	8 (42%)
Infectious disease (HIV, TB, malaria)	8 (42%)
Maternal and reproductive health	6 (32%)
Gender-based violence	5 (26%)
Early childhood development	6 (32%)
Education	4 (21%)
Unemployment and poverty	4 (21%)
Target beneficiaries	
Women	9 (47%)
Men	3 (16%)
Youth	16 (84%)
Urban populations	10 (52%)
Rural populations	13 (68%)
Frontline / community health workers	2 (11%)
Migrants / refugees / asylum seekers	1 (5%)
Methods of communication with community	
Text messaging (SMS)	5 (27%)
Phone calls	6 (32%)
Email	3 (16%)
WhatsApp	12 (63%)
Facebook	9 (47%)
In person: door-to-door	10 (52%)
In person: hospitals, clinics, schools, markets	9 (47%)

Findings

5 themes about the organizations were identified:

(1) They intimately understand community needs during the pandemic.

(2) They adapt to pandemic constraints to continue supporting vulnerable populations.

(3) They have established access and trust within their communities.

(4) They try to customize health education and information to address nuanced needs in communities served.

(5) They need external support to effectively respond to the pandemic.

Theme 1: Organizations intimately understand community needs during the pandemic.

The organizations that participated in our study serve a range of vulnerable populations in their communities and demonstrated a deep understanding of their needs during the pandemic. In addition to having extensive experience working in their communities, they have access to these populations for rapid needs assessments during times of crises. As the countries began to lock down, organizations immediately responded with efforts to understand the impact on their constituents, reaching out to existing clients, through WhatsApp groups and/or text messages. One organization leader described efforts to survey their beneficiaries.

"What we did in the early days of the lockdown is, we developed a survey, and we actually contacted a lot of the familiar individuals we knew within the learning site, to better understand their experiences of COVID." (IDI 8)

Organization leaders identified several major concerns that communities have faced during the pandemic. Aside from the direct impact on health from the spread of COVID-19, the primary concern raised by nearly all organization leaders was the economic impact of the pandemic, resulting in increased unemployment, food insecurity, and poverty.

One participant reported "*95 percent plus unemployment*" in some rural areas (IDI 5). Another expressed concern about the implications of urban job losses for rural areas reliant on remittances from towns and cities. Many worried about how families would be able to acquire food daily during imposed lockdown periods if they were expected to stay home.

"I think the economic concerns and food insecurity are a huge, huge concern. A lot of families… they're relying on child support grants and remittances from people working, from family members working in the cities or in the mines or whatever. And if those, like that income dries up, I think it's going to be very difficult." (IDI 5)

We observed general agreement across organization leaders that the most vulnerable would suffer the greatest. As one participant described *"[it is] the lowest of the lowest…who have been genuinely hit by the pandemic in the worst way possible" (IDI 17).*

Second, the shutdown of schools poses a major threat to the immediate health and wellbeing of children. Participants voiced concerns about children being on the streets instead of school. Since many schools provide meals for students, more children are now going hungry and are at increased risk of committing crime.

"It's easy to tell everyone else to go and stay in their own homes, but [for] kids on the streets, it's a hundred times worse because … they rely on donations or begging to get food." (IDI 6)

While some look forward to the reopening of schools, others pointed out that many schools "*don't even have ceiling for their classroom*," let alone the capacity to reopen safely and be able to prevent the spread of COVID-19 and others expressed concern about children being carriers of the virus and infecting other family members, particularly the elderly (IDI 13).

Third, another major concern is the lack of access to healthcare services during the pandemic and the implications for children and those suffering from chronic diseases including HIV and non-communicable diseases (NCDs). Disruptions to the transportation system have prevented community members from going to the hospital or retrieving medication. Disruptions to the supply chain of medications have put HIV patients at risk of not receiving their anti-retroviral medications and put children at risk of not receiving critical immunizations.

Finally, organizations expressed concerns about the resource and infrastructure constraints that limit their constituents' ability to protect themselves from the virus. These constraints have led to a knowledge-behavior gap. Even when organizations were able to successfully convey recommended preventative measures, their poorest constituents were not always able to follow through.

Nearly all organization leaders identified that, a significant barrier to following public health recommendations is limited infrastructure for handwashing Vulnerable populations in both urban and rural areas lack access to reliable clean running water.

"In the rural areas, where we have grantees, most of them either draw the water from the bore hole – water which is not treated – or from a stream. And when you come to urban areas, there is piped water. Although in some cases, the piped water or the pipes will run dry, and the people will have no water." (IDI 19)

Organization leaders also voiced concern about constituents' ability to comply with social distancing measures due to small living quarters and large families. One participant described common household setups within the communities served.

"So in one home, people are sharing, let's say, a home with 10 people. They will all be sharing the same kitchen. Inside the kitchen will be also a bedroom… So the social distance is completely impossible." (IDI 3)

Others noted the reliance on public transportation for carrying out essential tasks like purchasing food. Public transport is often overcrowded, and the 2 meters of distance between two persons recommended by the World Health Organization is often not possible to maintain.

Across the concerns expressed, organization leaders underscored how COVID-19 not only brings to light the preexisting socioeconomic inequality but exacerbates them. The pandemic draws attention to the disparities in access to sanitation infrastructure, housing and risks associated with employment. Furthermore, those with the fewest resources are those most at risk of contracting the virus given that basic needs like food security are a higher priority than contracting the virus.

Theme 2: Organizations adapt to pandemic constraints to continue supporting vulnerable populations.

Like their constituents, organizations experienced a swift and alarming impact of the pandemic on their daily operations. In the wake of the pandemic, organizations were forced to adapt their existing programs to operate remotely or with social distancing. Most staff members were asked to stay home and work through online platforms. For example, radio producers were trained to develop stories and interview through the phone, teachers began teaching through WhatsApp, and community health workers, who usually performed home visits, were asked to stay home until the organization could acquire personal protective equipment (PPE).

Nevertheless, since these organizations were already intimately connected with their constituents, they did their best to respond to the immediate needs identified. For example, one organization responded to the food insecurity experienced in their community by starting a food bank initiative. Another organization supporting HIV/AIDS patients acted quickly to ensure their patients had adequate supplies of anti-viral medication during lockdown. Others made efforts to provide extra psychosocial support to girls and young adults who usually receive in-person support.

Organizations took on new roles as part of their COVID-19 responses. In one case, a larger organization operating at a national level ended up supporting smaller grassroots organizations in their community education efforts.

"And what we've seen specifically with COVID is that, a lot of grassroots organizations may not have access to information that we as a national organization do. And rather than saying, we're going to speak on behalf of you … we basically tried to do a bit of knowledge translation in a way. Sort of say, we have access to these resources and this type of information, would this be helpful to you? And then send that information to organizations." (IDI 8)

Other organizations were approached by their government's health department to support local health facilities and government pandemic efforts. For example, one organization reported providing PPE to health workers on behalf of the government, while others sent nurses and social workers to aid government screening and testing programs.

"So the Department of Health has reached out to us. I mean, we're a small NGO. The Department of Health reached out to us to ask us to get them [community health workers] PPE. They don't have what they need." (IDI 5)

As the pandemic continued, organizations aimed to continue their pre-COVID delivery of services to the best of their ability. One leader described his organization as "*COVID adjacent*" *(IDI 1)*, because while they were not directly tackling the disease, they were focused on issues that have been *"amplified by the crisis"*. Leaders expressed concern that the sole focus on COVID-19 drew attention away from their primary goals, such as maternal and child health, HIV/AIDS, and poverty.

"Women still need to go to their ANC [antenatal care] appointments. Kids still need to get immunized… And if that gets disrupted and if other organizations and institutions are solely just focused on COVID, COVID, COVID there's going to be [many] gaps…and it will be difficult to regain that territory." (IDI 5)

Theme 3: Organizations play a unique role in reaching vulnerable populations due to greater access and trust within communities.

Despite their various goals and target populations, every organization in the study responded to the pandemic by engaging in COVID-19 awareness and education activities. Because of their established access within communities prior to the pandemic, organizations were well positioned to quickly provide pertinent health information to vulnerable and harder-to-reach groups.

Given constraints of lockdown and social distancing, most organizations used some form of social media to communicate to the public about COVID-19. WhatsApp and Facebook were the most commonly cited platforms and were deemed particularly effective at reaching younger populations.

However, participants emphasized that many groups cannot be reached through the internet or social media. Radio was a popular platform to target rural populations.

"There are some areas where you don't have the TV signals, so the radio has been so useful, especially, if [it is] in their local languages." (IDI 2)

Phone calls and text messages were also effective for many community members who owned phones, but not smart phones.

"[We communicate] through phones because the majority of people do own phones. They may not be smartphones, but they own phones. We also have print materials because not everybody may be able to get an SMS." (IDI 4)

While there were substantial efforts to provide health education using remote methods, many organizations still utilized their physical presence in the community, especially to communicate with groups that are more difficult to reach. Posters and pamphlets were key materials used to deliver health information. Several organizations have trained employees to conduct home visits for a variety of reasons. For example, one organization trained community health workers to conduct COVID screening and education during home visits for people with disabilities. A different organization visited families in order to talk about COVID and identify those who could use more resources, such as food baskets. Another organization that did door-to-door visits, found that many families had not heard of COVID-19.

"When [we] were doing home outreach most people were actually surprised. They didn't even know [about COVID-19]. They hadn't even heard because they don't have cellphones, they don't have WhatsApp… most people they needed to hear by word of mouth [which is] why we needed pamphlets…in both languages English and Xhosa so that people can easily understand." (IDI 3)

Nearly all participants emphasized that in addition to tapping into appropriate distribution channels, they needed to account for local norms to increase the likelihood that information would be embraced by recipients. Organization leaders shared that among more vulnerable populations including rural and migrant communities, there can be substantial mistrust in government and international sources.

"There's just generally trust issues with, not just our government, with a lot of governments in the world, where they've not always made the best decisions on behalf of people." (IDI 8)

"The government has been trying, of course, trying to tell the people, but when people lose trust and faith, it becomes a problem… When people lose trust, and they think that you are taking advantage of them, they'll ignore everything that you share." (IDI 7)

Organizations emphasized the importance of leveraging trusted sources of information within communities. Within rural areas, local leaders including religious and traditional leaders (e.g. chiefs and indunas), described as *"gatekeepers" (IDI 2)* have particular influence in communities, and organizations described efforts to ensure that key COVID-19 messaging would be disseminated through local leaders to overcome mistrust.

"The challenge of really reaching out to a lot of community leaders, so that those becomes our agents, our change agents. I think that's one of the major challenge, that we really need to involve them." (IDI 2)

The circulation of myths and misinformation about COVID-19 is one area in which collaboration with local leaders may be particularly effective.

"Making use of the tribal authorities – we've definitely found that it's been a very powerful way of spreading messages. We started asking if we could have a say in some of the traditional meetings that happen and sharing stuff with the headman, and then they've shared it on with the community, and the incidents has gone done dramatically since those messages. And they're also making use of the traditional healers. So having meetings with them and asking them if they can pass on messages, that's been one of the most powerful ways of passing messages on." (IDI 12)

Due to mixed reception of COVID-19 recommendations in some communities, it is especially important to develop relationships with local leaders to overcome resistance, while also acknowledging the associated challenges in doing so. One leader described that their organization *"straddle this kind of line" (IDI 9)* in developing community relationships.

"All of those things depend on relationships, but thankfully, we have a pretty good relationship with most of the people in those positions… And that's where kind of that us being neutral is quite helpful that is." (IDI 9)

Theme 4: Organizations try to customize health education and information to address nuanced needs in communities served.

Few of the organizations were able to create their own COVID-19 education materials for local distribution. All organizations relied on information from government or international sources including the World Health Organization (WHO) and United Nations Children's Fund (UNICEF) to share with their constituents. To increase the likelihood that information would be embraced, organization leaders described the need to customize information from these sources, not just through translations and simplification of language, but in contextual ways to "*meet the local acceptability, because they may not be accepted" (IDI 2)* in the communities they serve.

"We have [been]… introducing the materials from WHO, UNICEF, and all these other international organizations… when we get these materials, we have to customize them, so that they meet the norms and the ethics of our people" (IDI 2)

"We believe that not one cup fits them all. We'll always want to ensure that we have appropriately and generally accepted messages and culturally sensitive messages targeting our specific individuals or target audiences." (IDI 7)

There was consensus among organization leaders that health information customized for their intended audiences would be met with greater acceptance. The interviews revealed several populations that would especially benefit from targeted content.

First, rural communities need COVID-19 education resources that are applicable to the context in which they live. Many participants noted a rural-urban gap in information and resources about COVID-19. They described how rural culture, customs, and resource limitations have not been acknowledged in existing educational content. However, addressing the context of rural communities is key to effectively drawing attention to the COVID-19 messaging.

"There's a lot of myths, especially in the rural areas… Just like we have issues with menstrual hygiene. There's so many myths when you come to the rural areas. So it's the same with COVID-19. There are so many myths and it's the myths that mislead people. So it would be good to start with first explaining exactly what it is." (IDI 18)

Participants also emphasized that educational messages be actionable to bridge the knowledge-behavior disconnect caused by resource limitations among vulnerable groups. The primary example raised across participants is the disconnect between hand washing education and the availability of clean water and soap between different communities. Such messaging is ineffective if it does not provide viable alternatives that leverage available resources. As one organization leader recommended, the inclusion of resources like a tippy tap, a handwashing station designed for areas with no running water, are important to include in messaging upon which individuals can act.

"It [information] needs to be solution driven. So, something like tippy taps makes sense to showcase in some of our materials." (IDI 1)

Locally operating organizations are better able to address the resource gaps in actionable ways. As described by another participant, local organizations have *"done stuff about how to make hand washing bottles if you don't have water at home" (IDI 15).*

Additionally, in rural communities, people often face language barriers, highlighting the need for easily adaptable content to facilitate swift translation of resources. Organizations often bear the burden of translating educational material into local languages, which is labor intensive and challenging for organizations already short on funding and workforce.

"[In] Zambia, we have almost 73 languages, but we have to make sure that we translate them in the seven major languages, according to their regions." (IDI 2)

"I can honestly say that there was a significant gap in information that was not in English, which was quite frustrating because then you have to get it translated." (IDI 8)

Organizations also need educational resources suitable or adaptable for low literacy populations. Participants describe substantial rates of low literacy, indicating that pictures and animations, audio, and in-person teaching are important elements of health communication. This also means that the message of COVID-19 preventative measures needs to feel relevant to these groups of people, and not simply draw on abstract, unrelatable concepts.

"Population illiteracy is significantly high. I think off the top of my head, only approximately 10% finish high school ... So the people don't respond to having the science explained to them." (IDI 13)

Additionally, resources are needed that address the needs of patients with HIV and NCDs. Participants shared that many of the available resources on COVID-19 do not account for the intersection with other diseases. Organizations working with populations with HIV/AIDS and with other health risks expressed the desire for more targeted information to address beneficiary needs.

"None of it [COVID-19 education content] was really looking at COVID-19 in context. So, COVID-19 if you're HIV positive, COVID-19 if you have an NCD, COVID-19 if you have mental health issues. I think you can't really just talk about COVID-19 in our country without the broader context." (IDI 8)

Another organization leader highlighted how the experiences communities have faced with HIV and NCDs can shape their perspectives and behaviors related to COVID-19 in ways that need to be addressed.

"I think a lot of the people's mindsets currently is that, 'You know what? We've survived AIDS. We've survived TB [tuberculosis]. So we will survive COVID as well.' And I think that's why people aren't taking this whole thing serious." (IDI 16)

Migrants and refugees also face unique challenges when it comes to access to resources and trust. As the leader of one NGO focused on providing services to migrant communities described, "*migrant and community refugees, they are being excluded*", explaining how measures to mitigate against COVID-19 neglect to account for the challenges of those living in informal settlements where *"they share the toilets, they share the taps… there's no social distance" (IDI 9)*. Mistrust in information among displaced persons is also a particular barrier to overcome.

"Also remember, they've got trust issues. They've got issues from that at home… The migrant community is a very delicate community when it comes to trust issues." (IDI 9)

Finally, organizations need strategies to combat misinformation in the communities they serve. The majority of participants reported misinformation about COVID-19, either spread locally or through social media. Since local organizations are consistently connected with communities, they are aware of prevalent myths and motivated to dispel them. They report that it is challenging to combat misinformation due to its rapid spread.

"Fake news is a challenge… because people create things. They said if you drink the herb it's going to end COVID." (IDI 3)

Theme 5: Organizations need external support in the form of funding, technology support, and health expertise to effectively respond to the pandemic.

Despite their ability to quickly adapt to emerging constraints and serve their communities, the participating organizations described three major needs: funding, technology support, and health expertise.

Organizations have experienced crippling economic circumstances, with many now operating on reduced revenue streams. Losses in funding have not only limited organizations' ability to respond to the pandemic, but have also reduced their capacity to continue carrying out pre-pandemic activities. Declining funding has resulted in an inability to pay employees at a time when a strong workforce is needed to address the additional demands caused by the pandemic. The financial uncertainty has left organizations struggling with which activities to prioritize.

"It's hard for an NGO like [organization name] … We exist in a way to support needs of the community, but we also, you can't meet every need… But this is going to be significant need. And how do we kind of weigh that up against our existing work? … And if we were going to respond to COVID in a big way, we would need more employees…" (IDI 13)

The financial inability of organizations to meet the needs of their constituents results in a gap between the knowledge they provide about preventative measures and the ability of their beneficiaries to act on that information.

"People can't afford the mask. People can't afford small things that are needed that we are telling them about. We're preaching to people about the mask, but we're not providing those things to the people. So it's always good that what we are preaching, we should be in a position of providing people with that." (IDI 10)

The shift to remote means of communication increases the need for technology support, both in terms of greater access to the technology itself (e.g. a need for smartphones and tablet devices to better communicate with constituents) and support for using the technology.

"I think the shift to digital brings a lot of troubleshooting in terms of making sure you're using the right tools, making sure you do it in a way that's responsible… [so] that you're not excluding a whole range of the population because they're not online, as well as making sure that your use of digital space is a responsible one." (IDI 1)

Participants expressed concern that the shift to digital communication brought on by the pandemic may result in exclusion of certain portions of the population. Even for those with mobile devices, data costs remain high and there exists a need for *"data-free" (IDI 15)* platforms for constituents to access digital education content.

Lastly, organizations cited a need for health expertise and guidance in deciphering and distilling what one participant described as an "*information overload*" *(IDI 14)* and *"overwhelming influx of COVID information"* subsequently noting a desire for *"just [the] relevant information appropriate to you and to your constituency" (IDI 8).*

"[We are] basically drowning in information. There's just too much. I guess [we would like] help around pointing us to those sources that are not your obvious ones that we have covered and… helping us as a find how we can add value in that deluge of information." (IDI 8)

Alongside the desire for assistance with identifying relevant information, organization leaders expressed concerns about the changing nature of health recommendations, described as "*rules that [are] changing every day" (IDI 11). This* participant conjectured that the changing information may be fueling mistrust in COVID-19 information, referencing "*rising mistrust of the government information around mixed messages*" *(IDI 11).* Another participant emphasized a need for education materials that *"can be easily updated" (IDI 5)* as new information becomes available and *"updated quickly so that we can disseminate quickly."*

Organization leaders expressed a frustration with the degree of uncertainty and a lack of clarity of many recommendations and the course of the pandemic. As one participant reflected,

"I think the uncertainty of things is very concerning, because at the moment we don't know when this thing is going to end, with no cure. We don't know how long the funding is going to be put on hold… It's hard to plan…You don't know if you plan for something it's going to happen or should you wait another month." (IDI 6)

These findings have highlighted the extent to which local organizations respond to their community needs during a crisis, in addition to playing a critical role in providing health messaging to vulnerable populations. What has been emphasized is that without adequate support many of these programs are at risk. Ultimately, external support in the form of funding and expertise is needed to sustain organizations' impact within the communities they serve.

Discussion

Our study examines the role of non-governmental organizations in community-based responses to the COVID-19 pandemic. While this pandemic is unique in the breadth and severity of its impact globally, the responses exhibited by the organizations in this study reflect the role local organizations can play in help to protect and meet the needs of the most vulnerable members of society during a time of crisis. Organizations embedded within communities with a diverse set of focal areas and target populations play an important part in delivering targeted health information to risk groups that otherwise are unreached by mainstream channels of health education.

We found that community-based organizations are uniquely positioned to deliver effective health education given the following: their familiarity with local customs and norms; their awareness of local resource constraints; their ability to identify locally prevalent myths and misinformation; their knowledge of the needs facing specific risk groups (e.g., women, children, migrants, patients with HIV / NCDs, etc.); their access to local translators who can assist with translation of health information.

Organizations operating within communities can leverage established channels of communication including phone lists, social media platforms including WhatsApp and Facebook groups, radio, and in-person methods of communication. Organizations can also utilize their social networks to identify and leverage locally trusted sources of information, such as. local religious and traditional leaders, to assist with information dissemination.

While the potential for locally embedded organizations to reach the most vulnerable members of society exists, our findings reflect the challenges faced by these organizations in times of crisis. The loss of funding and lack of technology and health expertise to navigate an effective response renders organizations less effective in serving their at-risk beneficiaries.

These challenges illuminate several ways for government or external organizations to support NGO health education efforts. Given their role in providing targeted messages to the communities they serve, organizations would benefit from educational resources designed to be easily modified for various contexts. Since customizing health messages to match local language and culture is extremely labor intensive, modifiable content would allow organizations to make more efficient use of their staff, extending the reach of their health messaging. Organizations would also benefit from increased support in navigating technological and safety challenges in the pandemic setting. Ultimately, they need sustainable funding sources to continue operating and set long-term goals for their programs.

The purposive nature of our sampling presents limitations to the generalizability of our findings. We surveyed larger established organizations, the majority of which do operate nationally, and have the capacity to withstand the challenges of the pandemic in a way that smaller organizations may not. Our findings may not adequately reflect the situations faced by smaller NGOs and members of civil society. Even within our sample, we saw differences between national and regionally operating NGOs.

We acknowledge that interviewing the leaders of these organizations leads to inevitable biases due to a tendency to highlight the positive and productive aspects of their organization. While challenges to their operations were discussed, leaders may not have a comprehensive understanding

of issues that their employees may experience on the ground. Furthermore, they may be reluctant to discuss problems that they have not yet overcome. The interviews aimed to focus on challenges surrounding health education, but did not cover a variety of other barriers, such as local politics, competing local interests, and bureaucracy.

Conclusions

Our study contributes to a deeper understanding of the role of NGOs in providing needed support and customized health education for vulnerable communities during the COVID-19 public health crisis. As the pandemic continues to evolve, it will be critical for organizations to receive support to effectively deliver health education to hard-to-reach groups. Further research is needed to better understand the components of successful health education interventions by NGOs and the emerging needs of organizations and communities as the pandemic continues.

Abbreviations

IDI: In-depth interview

LMIC: Low- and Middle-Income Country

NCD: Non-communicable disease

NGO: Non-governmental organization

TB: Tuberculosis

UNICEF: United Nations Children's Fund

WHO: World Health Organization

Declarations

Ethics approval and consent to participate

Ethical approval for this study was obtained from the Institutional Review Board of Stanford University School of Medicine (Protocol ID 57373). Verbal informed consent was obtained from all nineteen participants before interviewing them.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Author Contributions

All authors contributed to the study design and writing of the manuscript. JJ led study conceptualization and design. KK conducted in-depth interviews. JJ, KZ, KK and NJ developed data collection tools and conducted data analysis.

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References

1. The Lancet. Redefining vulnerability in the era of COVID-19. The Lancet. 2020;395(10230):1089. doi:10.1016/S0140-6736(20)30757-1.
2. The Lancet. COVID-19 will not leave behind refugees and migrants. The Lancet. 2020;395(10230):1090. doi:10.1016/S0140-6736(20)30758-3.
3. Roberton T, Carter ED, Chou VB, Stegmuller AR, Jackson BD, Tam Y, Sawadogo-Lewis T, Walker N. Early estimates of the indirect effects of the COVID-19 pandemic on maternal and child mortality in low-income and middle-income countries: a modelling study. The Lancet Global Health. 2020;8(7):E901–8. doi:10.1016/S2214–109X(20)30229–1.
4. Lau LL, Hung N, Wilson K. COVID-19 response strategies: considering inequalities between and within countries. International Journal for Equity in Health. 2020;19:137. doi.org/10.1186/s12939-020-01254-9.
5. Meneses-Navarro S, Freyermuth-Enciso MG, Pelcastre-Villafuerte BE, et al. The challenges facing indigenous communities in Latin America as they confront the COVID-19 pandemic. International Journal for Equity in Health. 2020;19:63. doi.org/10.1186/s12939-020-01178-4.
6. Quaresima V, Naldini MM, Cirillo DM. The prospects for the SARS-CoV-2 pandemic in Africa. EMBO Mol Med Published online April 16, 2020; doi:10.15252/emmm.202012488.
7. Zhong B-L, Luo W, Li H-M, et al. Knowledge, attitudes, and practices towards COVID-19 among Chinese residents during the rapid rise period of the COVID-19 outbreak: a quick online cross-sectional survey. Int J Biol Sci. 2020;16(10):1745–52. doi:10.7150/ijbs.45221.
8. Austrian K, Abuya T. Nairobi Informal Settlements: COVID-19 Knowledge and Perceptions—Preliminary Findings. Population Council. 2020. doi:10.31899/pgy14.1003.
9. Arriola LR. Allison Namias Grossman. Ethnic marginalization and (non) compliance in public health emergencies. The Journal of Politics forthcoming; 2020; doi/10.1086/710784.
10. Logan C, Howard, Brian., and Gyimah-Boadi E Lessons from COVID-19 in Africa: Crisis and opportunity. APRM Governance Link Newsletter: Issue 8. 2020, May.
11. Costa K. The Cause of Panic at the Outbreak of COVID-19 in South Africa – A Comparative Analysis with Similar Outbreak in China and New York. 2020, March 13; doi.org/10.2139/ssrn.3613597.
12. Parkhurst JO. Louisiana Lush. The political environment of HIV: lessons from a comparison of Uganda and South Africa. Soc Sci Med 59(9):1913–24, 2004; doi.org/10.1016/j.socscimed.2004.02.026.
13. Muriisa RK, Jamil I. Addressing HIV/AIDS challenges in Uganda: Does social capital generation by NGOs matter? SAHARA-J. Journal of Social Aspects of HIV/AIDS. 2011;8(1):2–12. doi.org/10.1080/17290376.2011.9724978.
14. Shamu S, Slabbert J, Guloba G, Blom D, Khupakonke S, Masihleho N, et al. Linkage to care of HIV positive clients in a community based HIV counselling and testing programme: A success story of non-governmental organisations in a South African district. PLoS ONE. 2019;14(1):e0210826. doi.org/10.1371/journal.pone.0210826.
15. Kutalek R, Wang S, Fallah M, Wesseh CS. and Jeffrey Gilbert. "Ebola interventions: listen to communities.". The Lancet Global Health. 2015;3(3):e131. doi.org/10.1016/S2214-109X(15)70010-0.
16. Abramowitz S, Alane KE, McLean SL, McKune KL, Bardosh M, Fallah J, Monger K, Tehoungue, Patricia A. Omidian. "Community-centered responses to Ebola in urban Liberia: the view from below. PLoS Neglected Tropical Diseases. 2015;9(4):e0003706. doi.org/10.1371/journal.pntd.0003706.
17. Bedson J, Jalloh MF, Pedi D, Bah S, Owen K, Oniba A, Sangarie M, et al. "Community engagement in outbreak response: lessons from the 2014–2016 Ebola outbreak in Sierra Leone.". BMJ Global Health. 2020;5(8):e002145. doi.org/10.1136/bmjgh-2019-002145.
18. World Health Organization. 2019. Polio Endgame Strategy 2019–2023: Eradication, integration, certification, and containment. Geneva: World Health Organizations (WHO/Polio/19.04). License: CC BY-NC-SA 3.0 IGO. 2019.
19. Losey L, Ogden E, Bisrat F, Solomon R, Newberry D, Coates E, Ward D, et al. The CORE Group Polio Project: an overview of its history and its contributions to the global polio eradication initiative. Am J Trop Med Hyg. 2019;101(4):4–14. doi.org/10.4269/ajtmh.18-0916.
20. Krönke M. Africa's digital divide and the promise of e-learning. *Afrobarometer Policy Paper* 66. 2020. https://www.africaportal.org/publications/africas-digital-divide-and-promise-e-learning/. Accessed 16 Nov 2020.
21. The Impact of COVID-19 on African Civil Society Organizations: Challenges, Responses, and Opportunities. EPIC-Africa & @AfricanNGOs Report. 2020, June.

https://static1.squarespace.com/static/5638d8dbe4b087140cc9098d/t/5efabc7884a29a20185fcbaf/1593490570417/The+Impact+of+Covid-19+on+African+Civil+Society+Organizations.pdf. Accessed 16 Nov 2020.