

**Understanding the impacts of the COVID-19 pandemic response measures on
Deaf adults in Cape Town**

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DECLARATION

I, Charlotte Slome, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Signature: *Charlotte Slome*

Date: 23 January 2023

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PART A: PROTOCOL

SYNOPSIS

Project Title: Understanding the impacts of the COVID-19 pandemic response measures on Deaf adults in Cape Town.

Background: While there is evidence from other countries that the COVID-19 response measures negatively impacted Deaf people, there is currently no published research to understand the experiences and impact of COVID-19 on Deaf people in South Africa. This study aims to fill that gap. The Deaf population has been disadvantaged by the COVID-19 response measures including masking, lockdown, and social distancing policies; however, as mentioned, these findings have not been replicated within the South African context.

Study Purpose and Objectives: The proposed study aims to qualitatively investigate the ways in which the COVID-19 epidemic and its consequent control measures impacted Deaf adults in Cape Town, South Africa. This dissertation will add to the general body of knowledge in Deaf research and will specifically contribute evidence for how the COVID-19 pandemic and lockdown impacted Deaf people within the South African context. The research findings will provide evidence to defend the rights of Deaf people to accessible information and health, especially in times of global crisis. While this study will likely not have immediate practical implications for the Deaf community in Cape Town, its findings may later inform local health interventions to improve Deaf people's access to health and services in the midst of the pandemic and can potentially inform long-term disaster strategies as well. The objectives of the study are:

1. To explore the perspectives, attitudes, and experiences of Deaf people on the implementation of COVID-19 regulations (masking, hand hygiene and social distancing) and imposed lockdown rules
2. To assess the impact of Covid-19 policies on Deaf persons'
 - i. Ability to communicate (with family, friends, healthcare workers; remotely)
 - ii. Access to and quality of health and social services.
 - iii. Access to COVID-19-related information.

Study Design: To address the aim of investigating the ways in which the COVID-19 epidemic and its consequent control measures impacted the Deaf community in Cape Town, this research will utilise a qualitative study design. The targeted population of interest in this study is Deaf adults in Cape Town. To be eligible for the study, participants will have to meet the following criteria: over the age of 18 years, currently reside in Cape Town, self-identify as Deaf, communicate primarily with South African Sign Language (SASL), and agree to comply with COVID-19 safety precautions. Individuals who lack the capacity to consent or do not provide consent prior to data collection will be excluded from the study. Additionally, potential participants will be screened according to the risk category for COVID-19 infection using the Provincial Health Department Circular H77¹. Those who are considered high-risk for severe COVID-19 infection will be excluded from the study.

Data Collection: Semi-structured, in-depth interviews will be the main method of data collection. The interviews will be videotaped, if consented to by the participant, in order to capture the original, signed data as well as the consent process and the participant's consent agreement. Additionally, this study will use fieldnotes as a complimentary method of data collection to the interviews. Fieldnotes will be taken during and directly after the interview and will later be expanded and transferred to a secure, password protected Word document. The fieldnotes will be both descriptive and reflective in nature, as both are significant. The descriptive fieldnotes will benefit the interview data as they can provide additional context to frame and deepen participant's responses. My identity as an outsider to both the Deaf experience and the South African experience will influence the research process, which I will be able to document and reflect on through reflective fieldnotes. The generated fieldnotes will also be used for method triangulation to improve the validity of the interview data and improve the overall depth of the findings.

¹ Risk categories include Age >60; Chronic lung problems (moderate to severe asthma, previous complicated TB, etc.); Serious heart conditions; Those who are moderately or intermittently immunocompromised; Severe obesity (BMI >40); Underlying medical conditions, particularly if not well controlled, such as diabetes, renal failure, hypertension or liver disease and women more than 28 weeks pregnant.

Recruitment: Potential participants will be identified and recruited through a well-established relationship between several UCT researchers and the Deaf community in Cape Town. Recruitment will be carried out virtually as much as possible and will be the responsibility of the student, Charlotte Slome, to communicate with DCCT staff with regards to setting up interviews. If COVID-19 conditions and level allow for social gatherings at the time of recruitment, participants may be recruited through DCCT gatherings as well. Once recruited, interviews will be set up through WhatsApp or SMS. Recruitment will take place around April/May 2021, once ethics approval has been obtained. This study aims to enrol 15 to 20 participants and enrolment will be based on the concept of saturation.

Research Procedures: Interviews will be administered at the DCCT centre (Heathfield, Cape Town) in a venue that meets COVID-19 safety protocols. The DCCT centre was chosen as an appropriate site as it is a neutral space that is well known in the Deaf community and a place where members of the Deaf community feel safe, respected, and comfortable. The interview will be documented in video format with one frame of the participant and another frame of the interpreter. Agreement to comply with COVID-19 safety precautions is a prerequisite for participation. The risks associated with travel to and from the venue will be explained as well. Participants will be given a pamphlet from the Health Department (see Appendix F) that illustrates the five most important hygiene measures to prevent COVID-19 transmission and will be given an opportunity to ask any questions. Screening for COVID-19 symptoms (*Screening Tool B*, see Appendix E) will be conducted with all parties prior to conducting the interview. The interviewer and interpreter will self-administer the screening tool the day before and the morning of each interview. If any party presents COVID-19 symptoms, the interview will be cancelled, and the potentially infected person will be informed of the appropriate steps to follow (see Appendices D and F).

Ethics: Participation in this study is considered generally low risk. The content of the interview is not considered to cause any severe discomfort or harm to participants. The interview itself may serve as an opportunity for participants to unpack their experiences and understandings of

the COVID-19 epidemic, which could be beneficial. However, given that the COVID-19 pandemic has been particularly hard for some, it will be explained that if participants are experiencing any emotional distress from their participation, they should withdraw from the study and inform the research staff if they wish for a reference to trauma counselling. Participants will likely not experience any direct benefits from their participation in the study. Participants will be given a R150 stipend as compensation for their time and travel costs. The research findings will provide benefits mostly at the community level. These benefits will come from a better understanding of the ways in which the COVID-19 pandemic and response measures impacted Deaf adults in Cape Town and their experiences and perceptions of such. These findings can provide evidence for advocacy and awareness as well as inform local interventions tailored to the needs and experiences of Deaf adults and the Deaf community. The confidentiality of participants will be protected at all times during and after the study. The participant will be assured that the consent forms will be stored in a secure location separate from the data to protect their right to personal privacy. It will be made clear that anything the participant discusses will not be shared with anyone outside of the research team. Regarding the video recording of interviews, consent information will clearly explain the extent to which confidentiality can be assured and exactly how the recordings will be utilised. The recordings will only be available to research staff to allow for accurate translation and transcription. No identifiable information will be included in any forms of publication. The research site will be screened to ensure adequate privacy and safety. All collected data will be kept in a password protected drive.

SECTION ONE: INTRODUCTION

1.1 Background

In the third month of 2021, just over a year after the novel coronavirus (COVID-19) was first detected, the global number of confirmed cases surpassed another grim milestone of more than 120 million, as the global death toll from COVID-19 continues to climb, recently exceeding 2.6 million [1]. Initially discovered in Wuhan, China in December 2019 and declared a 'Public Health Emergency of International Concern' in January 2020 by the World Health Organization (WHO) [2], COVID-19, the disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has disrupted and forever changed every facet of society. While no one has been completely sheltered from the devastating reality of the coronavirus pandemic, socially disadvantaged populations have suffered disproportionately, not only from the direct impacts of the illness itself but also the indirect social, economic, and political consequences of the pandemic [3,4].

1.2 Impact of the COVID-19 pandemic on socially disadvantaged populations

Infection and mortality rates worse for vulnerable and disadvantaged populations

In South Africa, reports indicate that the prevalence of COVID-19 is higher among those residing in townships and informal settlements compared to wealthier residential areas. Nwosu and Oyenubi [5] reported that in June 2020, Khayelitsha, which makes up 6.7% of the Western Cape provincial population, accounted for more than 11% of provincial infections; whereas Stellenbosch accounted for 1.5% of provincial infections, even though the city represents 2.7% of the provincial population. Those living in poverty are not only at a heightened risk of contracting the virus but are also burdened with greater mortality rates. Statistics from 17 January 2021 presented in the Sunday Times demonstrate this, as the proportion of cases mortality rates in the Klipfontein sub-district and Khayelitsha were both above 5%, which is significantly higher than the northern sub-district, 2.37%, and national case proportions, 2.78% [3]. This data was echoed in a report investigating the impacts of the pandemic on disadvantaged and vulnerable populations in low- and lower middle-income countries (LMICs) published by the Imperial College COVID-19 response team, which demonstrated a significant trend that COVID-19 mortality risk increases with increasing poverty, estimating a 32 percent

increase in the probability of death in the poorest quintile compared to the wealthiest quintile [6].

Indirect consequences of the pandemic

It is important to note that many of the aforementioned consequences and inequalities were not created by the pandemic but rather, the pandemic-related circumstances amplified and exacerbated existing inequalities. The WHO defines social determinants of health as ‘the conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning and quality-of-life outcomes and risks’ [7]. In essence, these conditions make up the context within which health occurs. The influence of social determinants including economic stability, language and literacy in education, health and health care, and neighbourhood and the built environment, on COVID-19 incidence and health outcomes has become increasingly more clear as the pandemic unfolds. Nwosu and Oyenubi [5] examined poverty as a social determinant of health during COVID-19 in South Africa and found that while low- and no-income populations bear a disproportionately higher burden of poor health compared to high income populations, the magnitude of income-related health inequality during the COVID-19 pandemic was substantially worsened, six times what was recorded in 2017. Such economic hardships can contribute to inadequate housing, sanitation, nutrition, and health care access, which in turn can significantly affect health outcomes and overall wellbeing [8]. Moreover, the compounding of inequalities and discrimination, due to the intersectionality of socio-political identities, causes certain populations, such as persons with disabilities (PWDs), to be further burdened by the adverse impacts of the pandemic. Global data has shown that in many disaster and emergency situations, the mortality rate of the population of PWDs is two to four times higher than the that of the population of persons without disabilities, more so due to discriminatory policies and practices than the disability itself [9]. In the context of the pandemic, it has been estimated that PWDs living in cities are four times more likely to be injured or die compared to persons without disabilities [10].

1.3 Impacts of the COVID-19 pandemic on Deaf people

For Deaf communities across the globe, the pandemic and its disease-mitigation response strategies have exacerbated many existing disparities and created new, unique challenges. Historical systemic discrimination and oppression of Deaf people and signed languages, rooted in the medical model of deafness as a pathology instead of the culturo-linguistic model of Deafhood [11] has resulted in pervasive, multidimensional inequalities. Compared to those who can hear, Deaf people experience higher rates of poverty, unemployment, lower literacy levels, and educational attainment [12-14] – all of which impact their experience within the health system and their overall health and wellbeing. The prevalence of communicable and noncommunicable illnesses, mental health challenges, and social vulnerabilities are significantly higher in the Deaf population compared to the hearing population [15- 18]. These factors along with linguistic and communication barriers when accessing healthcare services results in Deaf patients experiencing higher incidences of misdiagnoses and incorrect treatment plans, increased medical costs, worse treatment adherence, insensitive or abusive patient-provider interactions, and lower levels of trust and health-seeking behaviours [14,18].

Several international studies have provided evidence that inequalities for Deaf persons have been worsened during the pandemic [16, 21]. While there has yet to be a South African COVID-19 study exclusively on Deaf persons, Ned et al [19] reports of discriminatory experiences by disabled persons during the pandemic. Given these findings and the existing inequalities impacting Deaf persons in South Africa, it is likely that the pandemic and its control measures have worsened such inequalities.

Communication barriers

One such challenge that has been exacerbated by COVID-19 response measures is barriers to communication. A global qualitative study into the experiences of PWDs during COVID-19 found a consistent trend among Deaf respondents who reported experiencing both direct and indirect consequences from masking mandates [20]. Deaf respondents from various African countries described how lipreading, which was listed as the most common method of communicating with hearing people, was thwarted by the use of face masks and in instances where they asked a hearing person to remove their mask, they were often met with anger and hostility, in turn

triggering feelings of confusion, fear, anxiety, and depression [20]. Deaf respondents from Latin American countries reported facing the same barriers due to masking, highlighting the negative impact it had on daily activities such as going to the supermarket or the pharmacy. Reports from Ghana and South Africa have reiterated these findings as well, whose participants described difficulties with masking as the mask loops wrap around and interfere with their hearing aids as well as communication barriers due to the mouth being covered [21, 19]. It is very important to highlight however, that although lip reading tends to be the most common communication technique when communicating with hearing non-signers, it is not preferred by Deaf people as it is extremely taxing and ineffective. For example, the accuracy of English lip reading is only 30 to 35 percent [22].

Access to information

For many Deaf adults, access to information is often insufficient, a consequence of a lifetime of ‘information marginalisation’ within the hearing world [13]. This relates not only to public information, but also to health information, including family medical history and the lack of access to personal medical information, due to communication barriers with health staff. Additionally, driven by systemic educational inequalities, low literacy levels tend to be more prevalent among Deaf people compared to hearing people in both high and LMICs [14,18,21,23]. For example, McKee et al. [24] found the prevalence of low health literacy among U.S. Deaf adults to be 6.9 times higher than hearing adults. Further, there are very few, and in some contexts no, public information sources that provide clear, reliable information for Deaf people. When considering health-related and scientific information, this number becomes even less.

With the implementation of lockdown and social distancing mandates along with the rapidly evolving knowledge base regarding the COVID-19 pandemic, the accessibility of online information and virtual social networks is more important now than ever before. Deaf people globally have reported a general absence of accessible information, in either signed languages or ‘plain language and pictograms,’ throughout the COVID-19 pandemic [20]. Information shapes people’s perceptions of and responses to the pandemic and its control measures, and

the absence of accessible information can have severe health consequences. Among U.S. Deaf adults, Kushalnagar et al. [25] found a correlation between respondent's reported level of knowledge about the pandemic response strategies and their compliance with and support of such strategies; one example being, Deaf adults who reported not knowing much about physical/social distancing were more likely to believe it is not an effective strategy to prevent the spread of the coronavirus. Deaf adults in Ghana expressed overwhelming feelings of fear, anxiety, isolation, and overall hardship as a result of information isolation [21]. In Uganda, two Deaf people had been shot at by authorities for being outside during curfew time; however, due to information isolation, these individuals were unaware of there being a curfew mandate at all [26]. These instances illustrate some of the ways in which information marginalisation during the COVID-19 pandemic can result in devastating and life-threatening health consequences.

1.4 Impact of COVID-19 for Deaf people in South Africa

The first COVID-19 case was reported in South Africa on 5 March 2020 and ten days later, on 15 March 2020, the President declared a National State of Disaster and introduced a series of public health measures aimed at preventing further spread of the virus to 'flatten the curve' [27]. These strategies included hand hygiene guidelines on how to properly wash one's hands and use sanitiser, a masking mandate requiring every person above the age of two to wear a face mask covering the mouth and nose at all times when outside the home, social distancing between non-household members of 1,8 meters at all times, and a national lockdown. The 21-day lockdown, that was later extended, prohibited all 'nonessential' movement outside the home. While such measures were deemed necessary for reducing the transmission of the virus and to avoid overwhelming the health system, the importance of community-informed responses seemed to be completely disregarded and there was an overall lack of public deliberation and community engagement in the planning and decision-making of disaster management response plans. A report produced by Ned et al. [19] on the experiences of PWDs in South Africa during the pandemic, of which 6 percent of respondents were Deaf, stated that there was no mention of collaboration or dialogue between disability persons' organisations (DPOs) and the Government regarding how to best meet the needs of disabled people during

the pandemic. While there is a gap in research around the Deaf experience during COVID-19, as part of the disability community, these instances resulted in various instances of discrimination against and inequalities for PWDs, including Deaf people.

The South African Deaf Community

There is currently no accurate statistic for the number of Deaf SASL users in South Africa. Estimates range from 500,000 to 1,5 million [12]. A majority of Deaf babies, 90 percent, are born to hearing parents who commonly have no knowledge of the Deaf community nor signed languages, which often hinders the child's linguistic development and learning. A standardised SASL teaching curriculum for Deaf learners was only approved and instituted in 2012, so most Deaf children before this time learned SASL from their peers, generating many distinct dialects across the country [22]. Due to educational barriers, the average reading and writing level among Deaf school leavers is at a Grade-4 equivalent, resulting in 75 percent of South African Deaf adults functionally illiterate and 70 percent of the Deaf population remains unemployed [22].

Cancellation and suspension of disability grants

In an early effort to concentrate resources to combat COVID-19, the Health Department suspended various primary health care services that were not considered a priority. One such suspended service was medical assessments, which are a prerequisite when applying for or renewing a disability grant through the South African Social Security Agency (SASSA) [28]. This decision meant that people whose grants expired around the time of the national lockdown or first-time applicants could not obtain a new medical assessment and thus, could not apply for or renew their grant. Four months later, on 8 July 2020, SASSA issued a statement outlining their 'phased-in strategy' to reinstate and extend temporary disability grants that lapsed during the national lockdown period to 30 October 2020 and to arrange medical assessments for new applicants. They stated that 'local (SASSA) offices will set aside two days per week to attend to disability related matters' [28]. However, this timeline was likely inadequate, considering that by 29 June 2020 there were more than 19,000 people awaiting medical assessments in the top

two of five priority groups alone for disability grant reinstatement. For instance, when a woman went to her local SASSA office in August in an attempt to find out when her grant application, which she submitted in March, would be processed, she was told to return on 15 September to assess whether she qualifies and if so, would still have to wait until 1 October to receive any payment [29].

Additionally, the SASSA offices themselves were ordered to close as the administration of social grants was also not deemed an essential service [29]. Upon closing their offices, all those with queries were instructed to contact their centralised call centre, with no acknowledgment of or alternate method for Deaf individuals. Applications to receive the Social Relief of Distress (SRD) grant for unemployed individuals were also designed to be telephonically administered, which undoubtedly discriminates against Deaf people, placing them at a greater disadvantage for accessing such economic relief. Although applications were later available through an online system, the initial exclusion of and discrimination against Deaf people cannot be ignored.

The failure to provide adequate social and financial support not only threatened the health and wellbeing of Deaf people but also was in violation of the right to access social security as provided in the Constitutional Bill of Rights. The Deaf Federation of South Africa (DeafSA) has estimated that at least 70 percent of Deaf people are unemployed, 40 percent maintain subsistence levels lower than that of their hearing counterparts, and up to 68 percent live in informal housing settlements [12]. Further, while there is no data specific to Deaf South Africans, a recent report on the experiences of PWDs in South Africa found that of the 59 percent of respondents who were employed, 36 percent stated they had to stop working as a result of the lockdown [19], indicating that there may be even more Deaf individuals in need of a temporary disability grant or other social security assistance.

Information and health for Deaf South Africans

For many of the same reasons discussed previously, the COVID-19 pandemic has left Deaf South Africans particularly vulnerable to information marginalisation and the detrimental consequences that result from insufficient information. To overcome the general inaccessibility of public information and mass media, Deaf community members often rely on one another as

sources of accessible information [30,31]. Historically, this occurred through in person gatherings, such as Deaf Clubs, and while in person Deaf events are still a central part of Deaf culture, the rising digitalisation of society has enabled Deaf community members to connect and share information through online platforms as well. Research has shown that Deaf adults in South Africa frequently use SMS text to communicate with each other [30]. More recently, Deaf adults in Cape Town identified the cell phone as their preferred tool for receiving and viewing health information [22]. While technology and social media have produced many incredible improvements in the accessibility of information for Deaf people, it has also become a source of vulnerability, especially during the pandemic period. The ability to make informed, evidence-based decisions is not automatically secured through informational access but also depends on the reliability and accuracy of such accessible information. Since the beginning of the COVID-19 pandemic, the propagation of misinformation, defined as ‘a claim of fact that is currently false due to lack of scientific evidence,’ has occurred at an alarmingly high rate [32]. The WHO has dubbed this an ‘infodemic,’ highlighting that the COVID-19 pandemic is the first in history where technology and social media are being used as information sources on a global scale [33].

Due to language and educational barriers, much of the information that is available to Deaf people online remains inaccessible, which limits the extent to which information is able to circulate through the online Deaf community. It also limits the amount and types of information a Deaf person has to corroborate the information they see online. On the other hand, because of the tight knit dynamics among Deaf people, the online Deaf community often acts as an information silo, rapidly amplifying the information that does happen to penetrate. These conditions may indicate that misinformation on social media has the potential to spread faster and be more accepted in the Deaf community compared to other groups.

1.5 The right to health for Deaf people

The WHO states that ‘disability is an intersecting issue of public health, human rights, and development’ [34]. The right to health, language, and equitable healthcare are established in myriad pieces of legislation. And yet, there have been many instances in which the rights of Deaf South Africans have been jeopardised or violated during the pandemic period.

As a signatory of the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006), South Africa has a duty to promote the accessibility of information and communication services through, for example, the provision of SASL information and interpretation services [18]. The Government seemed to acknowledge this duty by providing professional SASL interpreters for all presidential speeches and other important governmental announcements during the pandemic period. These were available for free on SABC and YouTube, indicating the Government's acknowledgment that providing information in SASL is essential. Additionally, the interpreters, as seen below, never wore face masks or any facial covering, highlighting the importance of clear facial expression in SASL and further signifying that masks and facial coverings may be a barrier for Deaf people.



Andiswa Gebashe, left, and Nicoline Du Toit, right, have been the SASL interpreters for the Presidential briefings throughout the pandemic.

In spite of this provision, during the initial stages of the national lockdown, the Government did not regard professional SASL interpretation services as an essential service and thus, these were unavailable [35]. This is in direct violation of article 25(b) of the UN CRPD, which cites interpreting services as one of the disability-specific important health services. The exclusion of interpreting services from the 'essential services' during the lockdown period almost certainly compromised Deaf persons' ability to access information and receive quality healthcare services and thus, violated their Constitutionally enshrined right to health and non-discriminatory, equitable healthcare.

1.6 Current gaps

While there is evidence of the negative impacts of the COVID-19 lockdown on Deaf people in other countries, there is currently no research being conducted to understand the experiences and impact of COVID-19 on Deaf people in South Africa. A majority of global research literature has centred on Deaf people from Western countries and in turn, contextualising their findings within Western societal constructs. However, this literature are often not applicable in non-Western contexts where the social and cultural understandings and experiences of Deaf people are vastly different. Given the unique positioning of South Africa and the diversity of the South African Deaf community, data from other countries are not necessarily applicable.

Furthermore, there is widespread erasure of Deaf experiences outside the general disability framework. This overlooks and invalidates the existence of Deaf people as a linguistic minority. Additionally, by not considering Deaf people apart from the rest of the disabled population, the distinctions between different Deaf communities as well as the complex, diverse identities of Deaf people have not been researched in the context of COVID-19.

Note on the Researcher: As an American student, now based in South Africa, I have a unique perspective and place in this research context. My undergraduate degree minor was in American Sign Language and Deaf Studies and as such, spent four years involved with the Deaf community in America. While no Deaf community, just as no Deaf person, is the same, my understanding of and tie to Deaf culture allows me to be well placed to conduct this research in a culturally sensitive and appropriate manner.

SECTION TWO: PURPOSE OF THE STUDY

2.1 Rationale and significance

Thus, the proposed study aims to qualitatively investigate the ways in which the COVID-19 epidemic and its consequent control measures impacted Deaf adults in Cape Town, South Africa. This dissertation will add to the general body of knowledge in Deaf research and will specifically contribute evidence for how the COVID-19 pandemic and lockdown impacted Deaf people within the South African context. The research findings will provide evidence to defend the rights of Deaf people to accessible information and health, especially in times of global

crisis. While this study will likely not have immediate practical implications for the Deaf community in Cape Town, its findings may later inform local health interventions to improve Deaf people's access to health and services in the midst of the pandemic and can potentially inform long-term disaster strategies as well.

2.2 Study objectives

1. To explore the perspectives, attitudes, and experiences of Deaf people on the implementation of COVID-19 regulations (masking, hand hygiene, and social distancing) and imposed lockdown rules.
2. To assess the impact of COVID-19 policies on Deaf persons'
 - i. Ability to communicate (with family, friends, healthcare workers; remotely)
 - ii. Access to and quality of health and social services.
 - iii. Access to COVID-19-related information.

SECTION THREE: METHODOLOGY

3.1 Research design

To address the aim of investigating the ways in which the COVID-19 epidemic and its consequent control measures impacted the Deaf community in Cape Town, this research will utilise a qualitative study design. Approaching public health research through a qualitative framework is crucial, as it creates space to uncover the complex relationships between a participant's experiences, perspectives, and the research problem, which are often hidden in quantitative studies [37].

A qualitative research design will be employed for this study. Qualitative data collection allows the researcher to understand the meanings which people attach to their actions, decisions, and beliefs within their social networks. Approaching this study with qualitative methods for data collection provides for an in-depth understanding of people's experiences of the COVID-19 pandemic, uncovering the ways in which they struggled as well as the ways in which their resiliency allowed them to survive such challenges. This naturalistic approach to research is ever more important when investigating the impacts of the COVID-19 pandemic on

the Deaf population, a group with often unique challenges as both a linguistic minority and part of the disability community.

3.2 Population and sampling

The targeted population of interest in this study is Deaf adults in Cape Town. To be eligible for the study, participants will have to meet the following criteria: over the age of 18 years, currently reside in Cape Town, self-identify as Deaf, communicate primarily with South African Sign Language (SASL), and agree to comply with COVID-19 safety precautions. Individuals who lack the capacity to consent or do not provide consent prior to data collection will be excluded from the study. Additionally, potential participants will be screened according to the risk category for COVID-19 infection using the Provincial Health Department Circular H77¹. Those who are considered high-risk for severe COVID-19 infection will be excluded from the study.

The sampling in this study will be purposive and include various pathways and resources to ensure maximum inclusion. Unlike quantitative research designs that aim to generalise data from the sample to a population, qualitative research aims to decisively select participants who are the best fit to respond to the research question [37]. The sample size will be based on the concept of saturation, where enrolment will be considered complete once the researcher deems that additional participants will not add to the quality or validity of the data [36]. Based on the length of this research, I expect to enrol 15 to 20 participants to reach saturation.

Potential participants will be identified and recruited through a well-established relationship between several UCT researchers and the Deaf community in Cape Town. The Deaf Community of Cape Town (DCCT) organisation will be used as a base to facilitate the recruitment of participants. Snowball sampling will be used as an additional method of recruitment.

Ulin et al. [36] defines snowball sampling as a technique for locating potential participants by asking others to identify other individuals they deem fit to address the research questions.

¹ Risk categories include Age >60; Chronic lung problems (moderate to severe asthma, previous complicated TB, etc.); Serious heart conditions; Those who are moderately or intermittently immunocompromised; Severe obesity (BMI >40); Underlying medical conditions, particularly if not well controlled, such as diabetes, renal failure, hypertension or liver disease and women more than 28 weeks pregnant.

Participant recruitment will be done virtually as much as possible. Using the DCCT organisation as a base, potential participants will be contacted by a DCCT representative through WhatsApp or SMS. If COVID-19 conditions and level allow for social gatherings at the time of recruitment, participants may be recruited through DCCT gatherings as well. Once recruited, interviews will be set up through WhatsApp or SMS.

3.3 Data collection methods

Research Personnel

The researcher has a Bachelor's degree in Psychological Sciences and American Sign Language / Deaf Studies. During her studies she conducted various interviews and small research projects in both English and American Sign Language. She is well versed in working with signed language interpreters in both formal and informal settings. Her membership in the American Deaf community and knowledge of Deaf cultural norms enables her to interact with Deaf people in a culturally appropriate manner. The researcher has also completed a Human Subjects Protection certification course offered through CITI Program.

Additionally, accredited SASL interpreters will be recruited for the study to assist with interviews and be a source for triangulation to ensure the translation and interpretation of the data are accurate during data analysis. Where feasible, these will be sourced through UCT but if not available, they will be sourced through organisations recognised as providing interpreting services (e.g. SASLIP). All interpreters are certified through the South African Translators Institute (SATI). To ensure confidentiality, interpreters will be required to sign a confidentiality agreement form (see Appendix B). The form will outline their responsibilities as part of the research staff and their ethical duty to protect the confidentiality of the participants by not sharing or discussing any research information with anyone outside of the research staff team.

Interviews

Semi-structured, in-depth interviews will be the main method of data collection. Interviews are the most common method of data collection in qualitative research [39]. Conducting the interview in a semi structured format, using predetermined guiding questions, allows for general consistency of discussed themes between participants while also granting the

participant freedom and agency to lead the discussion. Further, this interview style considers the participant as the expert, allowing the researcher to understand how the participant interprets their lived reality [36]. Additionally, a semi-structured format was deemed most appropriate as it allows the researcher room to probe and clarify throughout the discussion, which is especially important when conducting interviews across a language and cultural barrier. The interviews will be videotaped, if consented to by the participant, in order to capture the original, signed data as well as the consent process and the participant's consent agreement.

The interview guide will be piloted in one or two test interviews to ensure that the interview questions are not too difficult, the flow of the interview schedule is logical and that the participants feel comfortable being videotaped and interviewed in the presence of interpreters. These pilot interviews will also be used to ensure that all recording equipment is installed well.

Fieldnotes

In addition to conducting interviews, I will generate fieldnotes about my experience. Fieldnotes are a useful way for the researcher to document non-verbal, contextual information and further reflect on their experiences throughout the fieldwork process [36]. Fieldnotes will be taken during and directly after the interview and will later be expanded and transferred to a secure, password protected Word document. The fieldnotes will be both descriptive and reflective in nature as both are significant. A reflective researcher, according to Ulin et al. [36], is one that 'reflects critically on the research itself, not just the outcomes.' The descriptive fieldnotes will benefit the interview data as they can provide additional context to frame and deepen participant's responses. My identity as an outsider to both the Deaf experience and the South African experience will influence the research process, which I will be able to document and reflect on through reflective fieldnotes. The generated fieldnotes will also be used for method triangulation to improve the validity of the interview data and improve the overall depth of the findings.

Materials

Video recording equipment, two cameras and tripods, will be rented through the UCT Television Studio department. The interview guide was developed after a thorough review of the literature on the impacts of COVID-19 and lockdown generally and on the Deaf community in South Africa. Extensive discussions with her supervisors and input from Equal Health as to what was most important to address in the Deaf community informed the development of the interview guide as well. This study and the interview schedule are designed to fill a particular gap in the literature, as there are no studies that aim to understand the perspectives and impact of the COVID-19 pandemic on Deaf people in South Africa. The number of questions was a balance of seeking information and keeping the interview guide manageable so as not to tire respondents. Table 1 details how the different objectives are addressed through different questions in the Interview guide.

Table 1: Research objectives and their associated interview questions.

| Objective | Interview Question | Probes |
|---|--|---|
| 1. To explore the perspectives, attitudes, and experiences of Deaf people on the implementation of COVID-19 regulations (masking, hand hygiene, and social distancing) and imposed lockdown rules | Q1. How has the pandemic and its control measures impacted on your livelihood? | <i>Difference in income, physical or mental wellbeing, social support, feelings of loneliness</i> |
| | Q2. Tell me a bit about how you have experienced the pandemic and its control measures? | <i>Have you faced any challenges as a Deaf person that have worsened or improved during the pandemic?</i> |
| | Q3. How easy was it to comply with the control measures? | <i>Do you think they are important to follow to fight COVID-19? What do you think influences your ability or willingness to comply with control measures? Such as family/friends attitudes, living environment, mask interference with hearing aids</i> |
| | Q4. Have you experienced any situations where you felt more at risk due to the COVID-19 regulations? | <i>e.g. not being able to see facial expressions as clearly causing safety concerns How did you react in those situations?</i> |
| | Q5. How could the response to the pandemic have been managed differently? | <i>For Deaf people specifically? If you could make the rules, what would you have done differently?</i> |
| 2. To assess the impact of COVID-19 policies on Deaf persons' | | |
| i. Ability to communicate (with family, friends, healthcare workers; remotely) | Q6. How has your ability to communicate been impacted by COVID-19? | <i>In daily activities (e.g. grocery shopping); accessing professional interpreters; using informal interpreters; accessing services and communicating with health workers</i> |

| | | |
|--|---|---|
| ii. Access to and quality of health or social services | Q7. Did you access any health or social services (e.g. grants) during the pandemic? If so, what was your experience? | <i>Was your ability to access these services different from accessing services before the pandemic? Did you have access to an interpreter? Professional or informal? How was the quality of the services?</i> |
| iii. Access to COVID-19 related information | Q8. Who do you tend to rely on for COVID-19 information? | <i>What sources do you tend to use for information (social media; TV/radio/newspaper; SMS/WhatsApp groups; in-person conversations) Do you feel the Government provided sufficient access to COVID-19 related information for Deaf people? Including general information about the virus (transmission, risk, severity, symptoms); What the policies and restrictions are; Where to find information; Where to find testing sites and health services; What support resources and services are available; Information about the vaccines?</i> |

[Rationale for face-to-face data collection](#)

While the COVID-19 pandemic has drastically shifted mechanisms for primary data collection from traditional in person to remote administration, this research proposes that in-person data collection is necessary for this population as remote data collection will not be feasible given the unavoidable challenges and barriers to conducting remote interviews with Deaf participants in SASL. Telephonic interviews with Deaf participants are not possible as video is required in order for the interpreter and participant to communicate. However, remote video interviewing still poses significant operational, technical, and ethical challenges that will likely threaten the validity of the data.

Operational challenges

Conducting remote video interviews restricts participation to those who own or have access to a smart phone or computer, which not only limits the pool of potential participants but also introduces potential bias toward those with higher socio-economic status, education, and mobility. For the interview to be conducted via video, the participant must have access to a smart device that has sufficient capacity, even if provided with data, which has been a common issue reported in previous studies. Prior research in the Cape Town Deaf community has found

that for those who do have access to a cell phone, it is quite common that ownership is shared with friends or family, which may mean their access is conditional or limited [30]. These circumstances can often be an indicator of socioeconomic status and thus, is a potential source of bias. Further, given the diverse education levels of among Deaf adults, some may not be comfortable or confident navigating cell phones or technology. Most South African Deaf adults do not have access to the internet nor adequate computer literacy skills and 75 percent are functionally illiterate [22]. Van Pinxteren [30] illustrated that the possibilities of the cell phone for the Deaf community in Cape Town were strongly connected with the user's adaptability, level of education, and socio-economic circumstances. In this light, potential bias remains even among those who have access to the technology necessary to conduct remote video interviews.

Technical challenges

Technical difficulties are commonly experienced when collecting data via platforms such as Whatsapp, Skype, and Zoom, especially in low-resource communities. For example, even when data is provided to participants, the participant's often insufficient bandwidth has made remote interviews difficult to conduct as it interferes with the quality and consistency of connection and sound. Such technical problems can interfere with the flow of the conversation and threaten the quality of the data. These issues pose a greater threat when conducting interviews in signed languages as a majority of grammar comes from facial expressions so a clear, consistent image is necessary [11].

Ethical concerns

There are ethical concerns for conducting remote interviews as the participant may not have access to a private, uninterrupted space, which could impact their capacity and willingness to participate. Additionally, participants may feel uncomfortable sharing sensitive information with someone they have not met in person, which may cause unnecessary stress for the participant and may impact the depth of their responses.

3.5 Research procedures

Interviews will be administered at the DCCT centre (Heathfield, Cape Town) in a venue that meets COVID-19 safety protocols, which are outlined below in the Potential Risks section. The DCCT centre was chosen as an appropriate site as it is a neutral space that is well known in the

Deaf community and a place where members of the Deaf community feel safe, respected, and comfortable. In addition to meeting COVID-19 safety protocols, the privacy and lighting of the venue will be ensured (see SOP, Appendix D). The interview will be documented in video format with one frame of the participant and another frame of the interpreter.

As mentioned in Section 3.2, agreement to comply with COVID-19 safety precautions is a prerequisite for participation. The risks associated with travel to and from the venue will be explained as well. Participants will be given a pamphlet from the Health Department (see Appendix F) that illustrates the five most important hygiene measures to prevent COVID-19 transmission and will be given an opportunity to ask any questions. Screening for COVID-19 symptoms (*Screening Tool B*, see Appendix E) will be conducted with all parties prior to conducting the interview. The interviewer and interpreter will self-administer the screening tool the day before and the morning of each interview. The interviewer will contact the participant via WhatsApp or SMS to administer the screening tool the day before the interview. Additionally, the participant will be screened again by the interpreter in SASL prior to entering the interview site. If any party presents COVID-19 symptoms, the interview will be cancelled, and the potentially infected person will be informed of the appropriate steps to follow (see Appendices D and F).

Prior to beginning the interview, all study information will be presented to the participant in SASL along with a printed copy of the study information and the consent form in their choice of English, isiXhosa, and/or Afrikaans. The interviewer will go through the consent form and explain the purpose of the research, that their participation is entirely voluntary, and the data they provide will be fully confidential and anonymised, as well as their right to withdraw from the study at any stage if desired. Once the participant provides consent, the interviewer will begin the interview, following a predetermined topic guide (see Appendix D). Data collection will take approximately two hours per participant. The duration of each interview will be approximately one hour. The participant will be informed that they can pause the interview to take a break at any time. Field notes will be completed immediately following the conclusion of each interview. Participants will be given R150 to compensate them for their time and travel costs.

3.6 Data analysis

Interviews will be transcribed from SASL into written English by the researcher and analysed in the NVivo software. All data will be anonymised. In instances where the participant's language or meaning is unclear, the participant and/or interpreters will be contacted for clarification. Transcriptions will be examined to check for cultural and linguistic accuracy prior to analysis. The textual data, produced from interview transcripts and field notes, will go through a process of coding, which allows the researcher to identify key points in the data set and construct general themes [36].

Thematic analysis will be employed to identify and analyse common themes and patterns within the data [41]. I plan to use both an inductive and deductive approach to the data coding. The themes that I expect to emerge from the data such as difficulty accessing health or social services, misinformation, and factors impacting social determinants of health, will be applied to the data to generate codes and themes. However, most of the analysis I plan to do inductively, allowing the data to speak for itself by generating codes and themes from the content of the data instead of applying themes to the data. The data analysis process will be iterative, consisting of rounds of consultation with supervisors to discuss the coding process and decisions, which will also act as a form of quality control. Data analysis will also follow a grounded theory method, where theories and concepts arise from the data that are not preconceived, which makes this method well suited for exploratory research such as this study.

To promote trustworthiness, this study will follow the Nowell et al. [41] framework for ensuring rigour in thematic analysis, which outlines the process for conducting a methodologically sound analysis to generate insightful, rich, and trustworthy research findings. Nowell et al. [41] adopt Lincoln and Guba's (1985) trustworthiness criteria of credibility, transferability, dependability, and confirmability into every step of their analysis process. Triangulation of the data sources, including the interview transcripts and fieldnotes, along with the storage of the data will be done to promote the credibility of the findings. A detailed account of the research site and overall setting will be provided to establish transferability, which refers to the extent at which the findings are transferrable to other settings. An 'audit trail' [41] of the raw data, field notes, and transcripts will be maintained along with a reflexive journal in order to keep a self-critical account of the research process, specifically the data

coding process. This will promote dependability of the study, the extent at which the research can be replicated and produce similar findings. This process of reflexivity is especially important during data analysis as the researcher becomes the instrument for analysis, and it is their responsibility to be critical of their decisions to ensure that their personal perspective is not altering the interpretation and coding of the data.

SECTION FOUR: ETHICS

This study will follow the ethical principles and guidelines for the protection of human subjects in research expressed in The Belmont Report (1979) and in the Declaration of Helsinki (2013).

The three core ethical principles outlined in The Belmont Report are: respect for persons, beneficence, and justice. The dignity and autonomy of all research participants will be respected and protected. To meet the principle of beneficence, an effort will be made to minimise potential risks associated with participation while maximising potential benefits. Lastly, the risks and benefits resulting from this study will be distributed fairly to ensure justice.

4.1 Potential Risks and Benefits

Avoidance of harm is one of the fundamental ethical rules in research and is especially important in public health research [42]. Participation in this study is considered generally low risk. The content of the interview is not considered to cause any severe discomfort or harm to participants. The interview itself may serve as an opportunity for participants to unpack their experiences and understandings of the COVID-19 epidemic, which could be beneficial.

However, given that the COVID-19 pandemic has been particularly hard for some, it will be explained that if participants are experiencing any emotional distress from their participation, they should withdraw from the study and inform the research staff if they wish for a reference to trauma counselling. Counselling services will be identified through DCCT. The interpreters and the researcher will be responsible for identifying signs of distress in participants. Within the limits of the researcher and professional interpreter's experience, if either feels the participant is distressed, a referral will be offered.

The Deaf population is considered a vulnerable group in society and as such, their participation in research should be carefully considered to avoid incurring additional harm.

According to the Declaration of Helsinki [43], conducting research with vulnerable groups is warranted if the research is of priority to that group and cannot be conducted to the same effect in a non-vulnerable group. Given that hearing (non-vulnerable) members of society cannot accurately report on the Deaf experience being sought out for this research, and that the findings of this research aim to benefit the Deaf community, it is believed that inclusion of Deaf adults, as a vulnerable group, for this research is justified.

As discussed above, this research proposes in person data collection. Within the current context of lockdown and restrictions being Level 1, where social gatherings, gyms, and restaurants are now permitted, it is believed that this study will not cause participants to experience any risk more than what they would experience from daily activities. A detailed description of risk mitigation measures is outlined in the SOP (see Appendix D).

Participants will likely not experience any direct benefits from their participation in the study. The research findings will provide benefits mostly at the community level. These benefits will come from a better understanding of the ways in which the COVID-19 pandemic and response measures impacted Deaf adults in Cape Town and their experiences and perceptions of such. These findings can provide evidence for advocacy and awareness as well as inform local interventions tailored to the needs and experiences of Deaf adults and the Deaf community. Ultimately, I believe the risks associated with participation are minimal and the benefits of the research findings outweigh the risks.

4.2 Informed Consent

Informing participants so as to allow them to make informed judgments is a necessary step for ensuring *respect for persons* during research [42]. Aligned with the Declaration of Helsinki [43], participants will be adequately informed of the study's aims, methods, and the anticipated benefits and potential risks associated with participation. Participants in the study will be provided with all relevant study information in both a printed format in their choice of English, isiXhosa, and/or Afrikaans as well as in SASL before they choose to participate. They will be asked, in SASL, if they fully understand the research processes, its risks, and how the results will be used and will be given the opportunity to obtain further clarification if desired. The consent process will be taped to record the participant's decision as a 'signature' for informed consent.

Additionally, the language used in the written consent forms will be deliberately chosen based on its cultural and linguistic relevance. Participants will also be given the option to consent to video recording of the interview. Audio recording of the interpreter will be presented as an alternative option for participants who choose not to consent to video recording. A copy of the informed consent form can be found in Appendix A.

4.3 Voluntary Participation

It will be made clear to participants that their involvement in the study is completely voluntary. Participants will have the right to withdraw from the study at any point for any reason, which they do not have to disclose, and their withdrawal will not result in any negative consequences or judgement. The data collector, myself, has been trained and certified in research ethics regarding voluntary participation and the importance of not influencing participants in any way.

4.4 Justice

Justice, as outlined in The Belmont Report, refers to the researcher's ethical obligation to ensure that the benefits and burdens associated with participating in the study are distributed fairly. The recruitment strategy used will be carefully considered to avoid the possibility of systematically selecting individuals that are more vulnerable such as those living in poverty, racial and ethnic minorities, or any other potentially compromising factor.

4.5 Confidentiality

The confidentiality of participants will be protected at all times during and after the study. The participant will be assured that the consent forms, which include identifying details, will be stored in a secure location separate from the data to protect their right to personal privacy. It will be made clear that anything the participant discusses will not be shared with anyone outside of the research team. During the interviews at the DCCT centre, no outsiders will be allowed in the room to protect the confidentiality of the participant. All research staff, including interpreters, will sign a confidentiality agreement that they will not discuss or share research information with anyone outside of the research staff team.

Regarding the video recording of interviews, consent will clearly explain and outline the extent to which confidentiality can be assured and exactly how the recordings will be utilised. The recordings will only be available to research staff to allow for accurate translation and transcription. No identifiable information will be included in any forms of publication. Video recording is often the only reliable way to collect and store data in signed languages and to check the reliability of the informed consent process. Participants will be asked if they are willing to consent to their recording being kept for a potential future documentary. If so, the recording will not be destroyed and will remain in a secure location. If participants are uncomfortable with the storage of their recording, it will be destroyed after data analysis.

It is recognised that confidentiality may be threatened by the chosen recruitment strategies, including snowball sampling and recruiting via DCCT; however, given that this is a hard to reach population, snowball sampling was deemed the most appropriate method for recruitment. Participants will be reminded to respect the confidentiality of their peers by not influencing their decision to participate and respecting their privacy regarding their decision and experience in the study.

4.6 Data safety and monitoring

All collected data will be kept in a password protected drive. The data that will be stored includes video/audio recordings and transcripts of interviews and field notes, which will be appropriately labelled and dated for management. To protect the identity of the participants, consent forms will be kept in a secure, locked area, separate from the data, with controlled access for 5 years. Myself and my supervisors, Leslie London, and Myrna van Pinxteren, will have access to the data. Participant data will be allocated numerical IDs for anonymity.

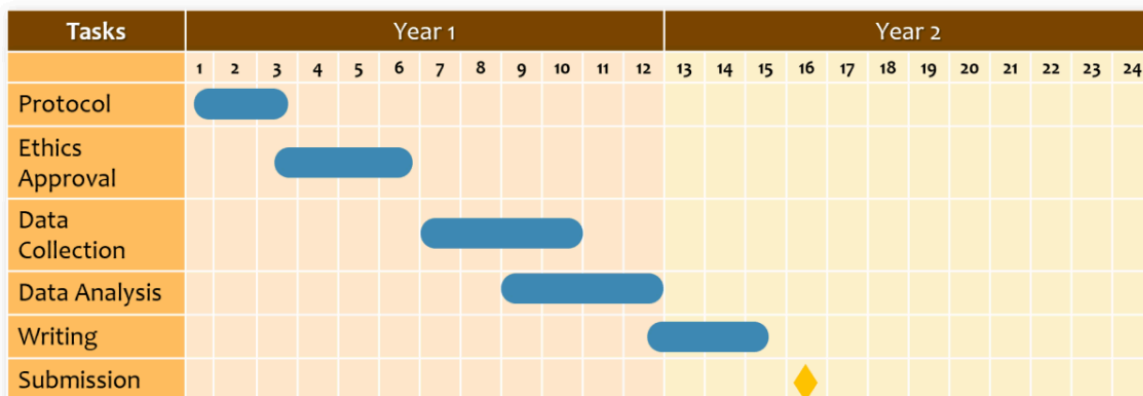
SECTION FIVE: LOGISTICS

5.1 Budget

| Item | Amount (units) | Cost per unit | Total cost | Comments |
|----------------------------------|-------------------|---------------|------------|--|
| Personnel | | | | |
| SASL Interpreter | 35 (hours) | R500/hr | R17,500 | Price dependent on amount of participants, interview time, and interpreter's fee |
| Translation of printed material | 3 (hours) | R100/hr | R300 | Translation into isiXhosa and Afrikaans |
| Equipment / Materials | | | | |
| Printed material | 50 (pages) | R0.76/pg | R38 | Includes: information sheets; consent forms |
| Hand sanitiser | 1 (250 ml) | R45 | R45 | Based on prices from Clicks |
| Surface disinfectant | 1 (250 ml) | R45 | R45 | |
| Face mask | 1 box (50 masks) | R199 | R199 | |
| Face shield | 21 | | | |
| Refreshments | -- | -- | R500 | All food/drink items will be individually packaged |
| Travel / Data | | | | |
| City centre to DCCT (Heathfield) | 20 (trips) | R350/trip | R7,000 | Based on Uber price |
| Compensation | 20 (participants) | R150 | R3,000 | |
| Data/airtime | 20 (participants) | R25 | R500 | |

5.2 Project timeline

Project Timeline



SECTION SIX: REFERENCES

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PART B: JOURNAL MANUSCRIPT

Understanding the impacts of the COVID-19 pandemic response measures on Deaf adults in Cape Town

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Abstract

International literature has evidenced that Deaf people have been disadvantaged during the COVID-19 pandemic; however, there is currently no research published within the South African context. This qualitative study investigated the ways in which the COVID-19 pandemic and its consequent response measures impacted Deaf adults in Cape Town. Semi-structured, in-depth interviews were held with fifteen Deaf/Hoh adults to explore the perspectives, attitudes, and experiences of Deaf people on the implementation of COVID-19 response measures, assess the impact of response measures on Deaf persons' ability to communicate, access to and quality of health and social services, and access to COVID-19-related information. The findings focus on information provision, the impact of communication barriers on daily life, and how the response measures impacted access to healthcare, and demonstrate how the needs of the Deaf community were overlooked and their voices disregarded during the planning of the national response, ultimately having detrimental consequences.

Keywords: Deaf; disability; COVID-19; information access; Africa; healthcare

Points of interest

- This study highlights the experiences of Deaf people in South Africa during the COVID-19 pandemic.
- Deaf adults expressed the lack of pandemic-related information in SASL and how this information deficit shaped their attitude towards the response measures.
- COVID-19 policies hindered access to and quality of healthcare services. Communication barriers during consultations led to miscommunication and confusion. However, Deaf people also showed resilience during these instances.
- Deaf organisations have been critical in providing information, support, and resources throughout the pandemic.
- Deaf people and Deaf organisations should be involved at all levels of governance, especially during disaster-response planning.

Introduction

COVID-19, the disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has disrupted and changed lives worldwide. Socially disadvantaged populations have suffered disproportionately, not only from the direct impacts of the illness itself but also the unintended effects of the implemented pandemic measures. Although there are some parallels between Deaf people's experience and that of other disabled persons, the centrality of language in the Deaf experience is often overlooked in wider disability studies (Kusters, 2011). This research aims to illuminate the unique pandemic experiences of and implications on South African Deaf adults.

In South Africa, a national State of Disaster was declared on 15 March 2020, under which a five-level alert system was implemented. Among the strictest in the world, the alert levels were designed to place degrees of restrictions on the freedoms of movement and assembly, economic sectors, and health and social services. On 26 March 2020 a shelter-in-place order was implemented under the Level 5 lockdown, requiring all citizens to remain in their homes except for certain permitted activities such as obtaining essential goods or services, seeking emergency or chronic medical attention, or collecting a social grant (for more details see: <https://www.gov.za/covid-19/about/about-alert-system>). The lockdown restrictions were accompanied by a series of public health measures focusing on individual behaviours. These included hand hygiene guidelines, a mask mandate requiring every person above the age of two to wear a face mask covering the mouth and nose whilst in public spaces, and a mandated social distance of 1,8 metres.

The United Nations (UN) Disability-Inclusive Response to COVID-19, published in May 2020, emphasised that persons with disabilities (PWDs) must be included in COVID-19 responses. Despite this, disability representatives were not included in South Africa's COVID-19 disaster management committees, and consequently, the developed policies failed to address the unique needs of PWDs (Mulibana, 2020).

The COVID-19 pandemic has compounded the well-documented marginalisation of PWDs. It is estimated that PWDs living in cities were four times more likely to be injured or die compared to persons without disabilities, more so due to discriminatory policies and practices than the disability itself (Pineda & Corburn, 2020). Discriminatory practices reported by PWDs during the pandemic in South Africa have included failure to receive government stimulus package, food parcels, and social grants (Ned et al., 2020).

In an early effort to concentrate resources, the national Department of Health suspended certain primary health care services that were not considered essential. One such service was the administering of medical assessments, a prerequisite when applying for or renewing a disability grant through the South African Social Security Agency (SASSA). Further, the SASSA offices themselves were ordered to close at the beginning of the lockdown (Voigt, 2020). Upon closing their offices, all those with queries were instructed to contact their centralised call centre, with no acknowledgment of or alternative method for Deaf individuals. Applications to receive the

Social Relief of Distress grant for unemployed individuals were designed to be telephonically administered, thus further disadvantaging Deaf people in accessing economic relief.

The prevalence of deafness is difficult to ascertain, but estimates from recent South African studies range from 4.6% to 8.9% (London et al., 2020). It is further estimated that between 500,000 and 1.5 million South Africans are ‘Deaf,’ which refers to deaf people whose primary language is South African Sign Language (SASL) and identify as members of the Deaf community, a culturo-linguistic group that shares common values, norms, behaviours, traditions, and language (Heap & Morgans, 2006). Due to systemic barriers and discrimination, compared to those who can hear, Deaf people experience higher rates of poverty, unemployment, lower literacy levels, and educational attainment (Chinthorn et al., 2016) – all of which impact their experience within the health system and their overall health and well-being.

Gap in literature

While there is evidence of the negative impacts of the COVID-19 lockdown on Deaf people in other countries, there is currently no research published which seeks to understand the experiences and impacts of COVID-19 on Deaf people in South Africa. The aim of this study was to assess the impact of COVID-19 policies on Deaf persons’ access to pandemic-related information, ability to communicate, and access to health and social services.

Research process

Study design and setting

This study employed a qualitative methodology. Participants were recruited through the Deaf Community of Cape Town (DCCT). Unlike most other linguistic groups, the Deaf community is a population without a geographic base, making Deaf organisations, like DCCT, a central node in their social networks (Heap, 2003). Founded in 1987 as a nongovernmental organisation (NGO) by Deaf people, for Deaf people, DCCT works to address the needs of Deaf people and the Deaf community in the Western Cape. Those with voting powers on the executive committee are all Deaf members. Members of the Deaf community can attend DCCT for counselling services, employment opportunities, skill-building, empowerment programmes, and more.

Interviews were conducted in a private room at the DCCT centre in Heathfield. The interview site was selected after ensuring it met both SASL-specific requirements (e.g. good lighting, low background noise and distractions) and COVID-19 precautions, based on national guidelines.

Population and sampling

The target population was Deaf/Hard-of-hearing (Hoh) adults in Cape Town. A purposive sampling process was used to recruit participants, allowing the researcher to generate a sample from the targeted population that was both accessible and met the inclusion criteria (Ulin et al., 2005). For inclusion, participants had to be over eighteen years, residing in Cape Town, identify as Deaf or Hoh, communicate primarily in SASL, and agree to comply with COVID-19 safety

precautions. Originally, those above 60 were considered high-risk for COVID-19 infection and thus, were excluded from the study. However, during recruitment DCCT held an event for the elderly and the study recruiter selected a few to be participants. Given that these individuals were already attending DCCT, we believed participation in the study posed no additional COVID-19-related threat and as such, they were included. The sample size was based on the concept of saturation, as outlined by Saunders et al., (2018), whereby after the fifteenth interview, no additional data were introduced by participants.

Data collection

Data were collected through semi-structured, in-depth interviews. The interview schedule was developed after thorough review of literature on the impacts of the pandemic on the South African Deaf community, extensive discussions amongst the research team, and input from Equal Health. Based on feedback from the two pilot interviewees and interpreters, the interview guide was shortened slightly to ensure questions remained relevant to the subject and participants would not be fatigued. Pilot interviews were ultimately not included.

During the interview, participants were asked to describe their experience of the pandemic and its response measures, the impact on their ability to communicate and access services, and their ability to access COVID-19-related information. Interviews were conducted in English and SASL with the use of two professional SASL interpreters, certified through the South African Translators Institute (SATI). Both interpreters are formally trained SASL interpreters working at the University. They were additionally trained in research ethics and briefed about the study prior to starting. Each session was videotaped in order to capture the original signed data, with one frame on the interviewee and another frame on the interpreter. Observational fieldnotes were generated as a complimentary method of data collection. Interview recordings were transcribed from SASL into written English by the researcher. In instances where word choice or meaning was unclear, the researcher would discuss with interpreters as a means of quality control, to ensure the translations were accurate.

Data analysis

The textual data were analysed using thematic analysis. Transcriptions were reviewed iteratively and thematically coded and stored in NVivo. The initial round of coding was done deductively, where themes related to the study objectives were applied to the data to generate codes. A subsequent process of inductive coding allowed codes and themes to emerge from the content of the data. The data analysis process followed the six steps of thematic analysis as defined by Braun and Clarke (2012): familiarizing yourself with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; producing the report. Several rounds of consultation with co-authors occurred to discuss the generated themes and interpretations. The findings were reviewed with a DCCT representative and interpreters to gain additional context and insight. Discussions around DCCT's role in providing support to the community and the level of support they received from the Government and other organisations, their process of

collecting and disseminating information, and their experience of the pandemic as an organisation further contextualised the themes.

Ethical considerations

The consent form was informed by previously conducted studies with the Cape Town Deaf community and was piloted and adjusted based on participant feedback. The researcher and interpreter discussed the consent process with the participant prior to the interview, which was videotaped to record the participants' decision as a signature for informed consent, in order to capture the original data. Participants were given the opportunity to consent to their interview being kept on file for a potential future documentary. Participants were given a copy of the information sheet in local languages English, isiXhosa, or Afrikaans. Interpreters signed a confidentiality agreement, stating they would not discuss nor share research information with anyone outside the research team. Ethical clearance to conduct the study was obtained from the University of Cape Town's Human Rights and Ethics Committee (198/2021). Recognising the importance of trustworthiness in research, all interviews were conducted by the same researcher and followed the same procedure, thus, minimising the risk of compromising the integrity of the data.

Results

Fifteen interviews were conducted between September and October 2021. Participants' ages ranged between 26 and 67 years. Eleven participants identified as women, five as men. Six were unemployed at the time of interviews, while nine were employed. Twelve participants were Deaf and three were Hoh. The average education level was Grade 8 (range from Grade 4 to Grade 12).

Table 1. Participant Demographics

| <i>Participant number (15)</i> | <i>Sex</i> | <i>Age (years)</i> | <i>Employment status</i> | <i>Education level</i> | <i>Deaf status</i> |
|--------------------------------|------------|--------------------|--------------------------|------------------------|--------------------|
| <i>Participant 1</i> | F | 60 | Unemployed | Grade 8 | Deaf |
| <i>Participant 2</i> | F | 67 | Unemployed | Grade 8 | Hoh |
| <i>Participant 3</i> | F | 38 | Employed | Grade 11 | Deaf |
| <i>Participant 4</i> | F | 63 | Unemployed | Grade 6 | Deaf |
| <i>Participant 5</i> | M | 41 | Unemployed | Grade 8 | Deaf |
| <i>Participant 6</i> | F | 26 | Unemployed | Grade 9 | Deaf |
| <i>Participant 7</i> | M | 30 | Employed | Grade 10 | Deaf |
| <i>Participant 8</i> | F | 45 | Employed | Grade 12 | Deaf |
| <i>Participant 9</i> | F | 26 | Employed | Grade 9 | Hoh |
| <i>Participant 10</i> | M | 45 | Employed | Grade 7 | Deaf |
| <i>Participant 11</i> | F | 47 | Employed | Grade 8 | Hoh |
| <i>Participant 12</i> | F | 55 | Employed | Grade 9 | Deaf |
| <i>Participant 13</i> | F | 58 | Employed | Grade 4 | Deaf |
| <i>Participant 14</i> | M | 47 | Unemployed | Grade 5 | Deaf |
| <i>Participant 15</i> | M | 45 | Employed | Grade 8 | Deaf |

Three pertinent themes emerged from data analysis: (1) information provision and communication, (2) the impact of communication barriers on daily life, and (3) the impact of response measures on access to care. Each theme is discussed below, prefaced by findings about Deaf people's daily experiences during COVID-19.

Contextual background: Daily experiences of Deaf people during COVID-19

The COVID-19 response measures, specifically the lockdown, had a devastating socio-economic impact on Deaf people. Participants who lost their jobs due to the business closures described the financial hardship of losing their income:

My workplace laid-off everyone over 60 because they didn't want to take responsibility if one of us got the virus. I had to apply for a pension, but the money I made while working was much better. It wasn't easy, my standard of living went down. (Participant 4/F/63)

I used to work at a hotel before COVID, but they closed in March 2020 and sent us all home. The managers asked us to write down our contact information and said they would call, but six months passed, and they never called. They finally called my mom in March 2021 to facilitate the UIF process. During that time, I had no income. (Participant 14/M/47)

Ten participants lived with only hearing family members not proficient in SASL, which was particularly difficult during the shelter-in-place period, as they lost contact with their signing community and faced social isolation within the home:

My brothers sign a little, but it isn't much. They try to explain what the news is saying. I could have full communication with my late mother, but my brothers sign very slow. But I have to accept the situation. (Participant 7/M/30)

One participant expressed how she did not feel terribly affected by the lockdown regulations because they did not drastically conflict with her regular living habits:

I don't know. I'm able to sanitize and adhere to the rules. So, I haven't been infected or affected by it. During lockdown it was like no worries for me because I don't drink or smoke. Just tea or coffee, that's my thing. (Participant 2/F/67)

Others described how the lockdown disrupted their daily lives and social support systems, the fear around the severity of the disease itself, and the grief from losing loved ones:

I was sad because a lot of people I know passed way from COVID. One person from my church contracted COVID, which was an overwhelming situation because I had to self-isolate and stay home. It felt like I was in prison. (Participant 1/F/60)

I was scared because I have health problems. If I got infected by COVID, I would die. With the lockdown, I wanted to know what was happening. Then I started hearing that people are dying (Participant15/M/45)

One participant described how feeling informed eased her fears:

When I looked at how many people were getting sick, I tried to be positive. I felt there was no need to be scared because I had done my research, I read the rules and regulations (Participant6/F/26)

Information provision during the COVID-19 pandemic

Four sub-themes were identified that described participants' experiences accessing information during the pandemic: sources of information and information seeking behaviour, the lack of accessible information, the risk posed to Deaf persons' health and safety due to an information deficit, and DCCT's role in information provision for the Deaf community.

All participants had general knowledge of COVID-19 measures such as social distancing, hand hygiene, and masking. Participants were asked to share the sources they relied upon for COVID-related information. Fourteen participants identified DCCT as a main source of information. The interpreted news was the second most common source of information, identified by ten participants. In Cape Town, SABC and ETV channels have an interpreter every day for 30 minutes, at 5:30pm and 8pm. Many participants expressed frustration regarding the inconsistency and inadequacy of the interpreted news, stating it was not enough to provide full access to information:

30 minutes only? That's not enough, that's not the details. On SABC1 we would be missing interpreters. During lockdown the interpreter wasn't on at night. Hearing people can access the news any time of the day, but for Deaf people, our time is limited. They need to have more interpreters on the news channels. (Participant 8/F/45)

Accessing information was especially difficult during shelter-in-place orders as the structures they generally relied on for social interaction and information, such as DCCT, were closed. Only three participants mentioned getting some information from their hearing family members; however, they all explained that this information was limited and not detailed because their family members were not proficient in SASL. After being laid-off at the beginning of the lockdown, Participant 4 reflected on her experience accessing information while living at home with her hearing daughter, who was not proficient in SASL:

I had no information while I was staying at home during lockdown levels 4 and 5. My workplace laid-off those over 60 in March 2020 and we only went back in June. During that time I had no information. I just waited until Government opened the levels, then DCCT came and provided information. (Participant 4/F/63)

This experience highlights the importance of recognising the intersectionality of deafness and age that may heighten the vulnerability of older Deaf/Hoh adults. Participants were frustrated with the discrepancy between the information they had access to compared to their hearing counterparts. A participant who worked with other Deaf adults described how she had to fight for the same information that was provided to her hearing co-workers:

My workplace explained about COVID but not with an interpreter and using basic signs, so we didn't understand a lot. When we asked what the manager said, they would say 'you must wait... you must wait.' But it's important, I need to know now!
(Participant3/F/38)

Further frustration and disappointment of being ignored by hearing people when asking for information was expressed by other participants:

When Deaf people ask, 'what does that mean,' they'll tell you one word and that's all the information they share. You can see the person is sharing a lot of information but when you ask, they give you one or two words. (Participant 8/F/45)

For Deaf people, being perpetually left out of conversations and kept from information among non-signing hearing people, often referred to as the 'dinner table syndrome,' is nothing new (Meek, 2020). However, deprivation from the discourse surrounding COVID-19 can lead to a life-threatening information deficit. The efficacy of social distancing and mask-wearing in mitigating the risk of COVID-19 infection and transmission is well evidenced (Kwon et al., 2021). Despite this, several participants reported not masking or social distancing during the initial stages of the pandemic, thus increasing their risk of COVID-19 infection. They attributed their behaviour to being ill-informed of the restrictions and the importance of adherence as a means of protection. Participant 4 shared that in the beginning of the lockdown, during March and April 2020, she did not adhere to imposed restrictions because she did not realise the threat that COVID-19 posed:

But I said, 'what is dangerous?' I was told to stay home for 6 weeks but I'd go to visit my friends because I didn't know what is this Corona. What does it mean? I didn't really understand anything. (Participant 4/F/63)

After participants received information in SASL, they were able to understand both the severity of the disease itself, as well as how the response measures could protect them from infection, and thus began to comply with preventive strategies. Participant 4 recalled how she had to wait until June 2020, when DCCT was allowed to open under Level 3 restrictions, to receive any intelligible information about COVID-19 and the pandemic response measures. She stated that during shelter-in-place orders, from March until May 2020, she had no information:

After a long time, I came to DCCT and they shared information in SASL and I was like, 'Oh, it's Corona, it's dangerous, it's an infection.' So, I say thank you to DCCT because

it was only when they started sharing information that I understood. After I understood, I became very strict and careful. (Participant 4/F/63)

DCCT played a pivotal role in providing community-based support throughout the pandemic. As DCCT was not considered an essential service under the initial lockdown restrictions, the organisation had to close its doors March-June 2020. During this time, DCCT created COVID-awareness videos in SASL, using information from the televised Presidential addresses and the Department of Health's website. These videos were disseminated through Facebook and WhatsApp. Almost all participants referred to these videos as one of their main sources of information. One participant emphasised the importance of DCCT's role in information provision, given the inaccessibility of other information sources:

There are many Deaf people who only understand what's happening because of the information DCCT shares, because Deaf people don't have equal access to the same information as hearing people. (Participant 15/M/45)

When restrictions began to ease and in-person gatherings were permitted, DCCT held events both at the centre and within communities to further promote education around COVID-19. The positive impact these outreach efforts had were expressed:

DCCT would travel and have information sessions to explain why we must socially distance, sanitise, and mask. They also gave us bags with masks and sanitisers because they said they don't want Deaf people to die, we want to protect you. Then I started to really believe. (Participant 4/F/63)

DCCT served as a hub for the Deaf community, where they could come together to support one another and share information. This especially benefited those employed at DCCT, as they were able to regularly share and discuss COVID-related information and develop their understanding. Several DCCT employees described the process of information sharing among staff and how such information was further disseminated to the rest of the community:

Sometimes there are bad interpreters on the news, so we come to work and discuss with each other and they explain what was stated on TV in a more clear and deeper way (Participant 11/F/47)

Staff members would get the information and then do a presentation teaching us about Corona and how to protect ourselves. Basically, it was a training session for us so we could then share information with other Deaf people. (Participant 8/F/45)

Participants also expressed how important it was for them to be able to support their Deaf peers, recognising how difficult it can be for some to access information:

If you don't understand anything about COVID and I have some information, I love to share. Mostly to help Deaf people because it's very difficult to understand what COVID

is. They just thought it's not safe, but knowing in detail what it entails and how it spreads, this is what we need as Deaf people, to be aware and have more information about COVID. (Participant 6/F/26)

Participants described the inaccessibility of COVID-19 information and the subsequent information deficit, which influenced their behaviours and attitudes towards the response measures. In the face of such barriers to accessing information, participants also revealed the strategies they adopted to overcome and navigate the pandemic, both on a community and an individual level. The organised actions of DCCT were crucial in providing accurate and understandable COVID-related information and support to the Deaf community. Information sharing on an individual level was also commonly discussed and participants described the personal responsibility they felt to share all the information they had with their Deaf peers.

The impact of communication barriers on daily life

Participants described how the response measures affected their ability to communicate, with both hearing and other Deaf people, and the accessibility of basic services. While communicating with hearing non-signers has always been challenging, the response measures, and in particular masking mandates, exacerbated these existing communication barriers. Most participants relied on lip-reading prior to the pandemic and although this communication mode is not ideal due to its taxing nature and ineffectiveness, masking completely thwarted the ability to lip-read. Participants described facing hostile reactions from hearing people when they were asked to remove their mask or for clarification of what was said.

Due to the communication barriers created by masking, participants had to resort to written communication. However, written communication presented its own challenges. Grammatical differences between SASL and the local languages (English, isiXhosa, and Afrikaans) often make it difficult to discern what is written. Additionally, due to the social distancing mandates and the fear of infection, participants described how many people were hesitant to share pen and paper or get close enough to read their notes. Participant 13 reflected on the challenges she faced when communicating with hearing adults:

If I ask people to remove their mask, they refuse. So, I have to write things, but some would get angry. They'd say, 'What does this mean, what is this about?' Sometimes you just give up and have to go to the next person until you find someone who's understanding. (Participant 13/F/38)

While communication barriers with hearing people existed prior to the pandemic, masking created a novel challenge for Deaf people when communicating in SASL. A majority of grammar in signed languages is determined by facial expression (Elliott & Jacobs, 2013), and as such, having a mask that covers a large portion of one's face hinders communication. The miscommunication that occurred due to masking were discussed by one participant:

You must take off your mask when signing with other Deaf people. They need to see your lips and mouth. It's part of the language. If you cover your mouth, they get closer to you and think you're angry because the mask is covering your face and then you have to take it off and say no, I'm not angry. (Participant 11/F/47)

This placed many in a difficult predicament, having to choose between full communication and protecting themselves from infection. One participant shared how she navigated this challenge:

Some people had to take down their masks because it's for Deaf culture. For us Deaf, people we need to see you. Yes, I want to be protected but I also want to understand what you're saying. It made me anxious, but I would compensate by keeping social distancing (Participant 5/M/41)

Participants also noted that social distancing created a communication barrier because it goes against Deaf culture and customs. While it is easy to use one's voice to get the attention of a hearing person who may be facing the other way or not paying attention, to get the attention of a Deaf person often requires tapping them on the shoulder, flickering the lights, or moving around to the front of them, all of which could break social distancing rules. One participant captured this dilemma:

It was difficult. We must touch each other because we are Deaf. How am I going to call a Deaf person if they're focusing on something else and don't see me waving my hands? So, I have to tap them. (Participant 6/F/26)

Several others described how social distancing inhibited the important practice of physical touch in Deaf culture:

There's one thing with Deaf people – they'll say, 'Why are we hitting elbows? No, we need to hug.' They always forget about COVID, but we need to follow the rules. I would sometimes be concerned but I still hug them because this is how we communicate and love each other as Deaf people. (Participant 6/F/26)

Social distancing is difficult for Deaf people. Deaf people want to sit next to you, be close. I would always have something between us to make social distancing but then we can sign to each other. Because we are a close community, it's part of Deaf Culture. It's the Deaf way. (Participant 4/F/63)

The communication barriers caused by masking, social distancing, and lockdown policies also hindered participants' ability to do daily activities such as taking taxis, going to the bank, or dealing with social services like SASSA or police services. One participant described how masking-related communication barriers led her to get into a taxi traveling to the wrong suburb in Cape Town:

It was very difficult and challenging to communicate. When you're asking a taxi, you have to write down everything. 'Where are you going;' 'I'm going to Cape Town.' Sometimes people would tell me the wrong taxi to get on. And that taxi goes to Sea Point and not Cape Town. So that was very stressful for me because of the masks. (Participant 8/F/45)

Several others described their negative experiences while accessing services with employees at SASSA offices and the police station:

I brought an interpreter with me to the SASSA office, but they said the interpreter must keep their mask on. We explained that we need to see each other's faces for facial expressions, but they refused. We tried to communicate with the mask on, but it was quite difficult. Some places, like SASSA, had their own rules about the mask so we just had to adhere to their rules. (Participant 5/M/41)

Communication has always been a problem at the police station. But now they only allow one person. I need the masks down to understand their facial expressions and how they can help me. I tried to put my mask down to communicate but they told me to put it back on. (Participant 7/M/30)

These COVID-19 mandates are often enforced by security personnel employed by SASSA and police services, who are not trained to make accommodations for people with different needs.

The practical implications of COVID-19 response measures on Deaf persons' experiences of health services

Nearly all participants (n=14) accessed health services at some point during the pandemic prior to interviewing. Three themes emerged from participants' experiences accessing health services including the refusal of interpreters, interpersonal communication barriers with providers, and COVID-19 vaccination experiences. During the initial stages of South Africa's lockdown, interpreting services were not deemed essential and thus, interpreters were barred from accompanying Deaf patients. Among the fourteen participants who accessed health services during the pandemic, ten expressed a desire to have an interpreter, but were unable to due to the restrictions. Participants described their experiences being denied an interpreter when accessing care:

We can't bring anyone, interpreters as well. When I went I said, 'I'm Deaf, this is my interpreter,' and they didn't allow the interpreter to even come in, so I was forced to go alone. (Participant 2/F/67)

When the ambulance came to take my husband to the hospital because he had COVID, I asked if my son could go with him because he's hearing and my husband is Hoh, but she said no, he needs to go alone. This was in January 2021. (Participant 12/F/55)

Among the three participants who were allowed to bring someone to interpret, only one was able to bring a professional interpreter. The other two were allowed to bring a family member.

Participant 14 explained that his mom always attends his monthly appointments:

There was no interpreter, so my mom went with me. The doctor would've sent me back because we struggle to communicate so my mom must come with. I have a monthly appointment and they know I'm Deaf so they would call me, but I can't hear, so my mom always comes to help me. (Participant 14/M/47)

Participant 3 described the challenge of having to rely on her daughter, who is not fluent in SASL, to attempt to bridge the language gap between herself and healthcare providers:

My daughter told them, 'My mom is Deaf and I'm the daughter' and they allowed her to come. She did try. It was a slow process to get information across, but we finally managed, and I got my medication. (Participant 3/F/38)

Due to the refusal of interpreters during health visits, many participants had negative experiences with healthcare workers who refused to make accommodations to facilitate communication.

Being unable to lip-read because of masks made it impossible for patients in the waiting room to see their name being called for their appointment. One participant detailed his experience:

I saw they were calling patient's names, but I couldn't see if mine had been called because they were wearing a mask. I wrote a note, but they said, 'No sorry, we can't hear you.' I asked them to please speak more clearly but the receptionist just started pointing. I was like, 'What does that mean? How are you communicating with me like that? I need you to put down your mask so I can communicate or write things down,' but they refused. There was a window too. 'If there's a window, why wouldn't you pull down your mask?' They said no and ignored me. (Participant 15/M/45)

His response illustrates how in the face of discrimination and barriers to access care, some Deaf people adapted their own creative strategies to assert themselves and be active agents. Another participant approached this conundrum by writing 'Deaf' on his medical folder:

The nurses think, 'how am I going to communicate with this person or call for the appointment?' They basically just shove the folder aside. We thought it would help to write 'Deaf' on my folder so they can lift it up instead of calling out the name so I can tell it's for me. So that's been a bit better lately. (Participant 10/M/45)

On the other hand, two participants had positive experiences because staff agreed to remove their masks so they could lipread. However, both participants attributed this to their existing relationship with the clinic staff:

The hospital knows I'm Hoh, so they know to take their mask off. There's an employee who has a Deaf family member and taught other staff how to communicate and interact

with Deaf patients. Whenever they see Deaf people, they make the announcement to say there's a Deaf person here, so the rest of the staff knows. (Participant 11/F/47)

Many had to resort to writing notes to communicate during consultations, as providers often refused to remove their masks. Among those that had to use written communication, the majority were dissatisfied with the experience. Poor literacy among the Deaf population and the technical nature of medical jargon makes it difficult for Deaf patients to understand what is written by healthcare workers. In addition, due to grammatical differences between the languages, many providers have difficulty understanding what is written by Deaf patients, creating confusion for both. The negative feelings that emerged from these confusing and belittling experiences were expressed:

Before COVID, communication was easier. Now with masks everywhere, I have to ask people to please write. But sometimes they would say, 'What are you writing here, what is this? I don't understand.' It would make me feel uneasy. Because of COVID this is my only option, you need to at least accept this means of communication from me. (Participant 6/F/26)

Not fully understanding the prescribed treatment because of providers' limited ability to communicate was a common experience:

The doctor changed my blood pressure tablets during Level 4, but the nurses wouldn't let me see the doctor and didn't explain why they changed the medication. They just brought the medication and told me to go home. The new tablets made me very dizzy so when I finally saw the doctor during Level 3 I told them I don't want to take this medication because I don't know what it's for and I'm afraid. (Participant 11/F/47)

I brought an interpreter with me, but the nurses said only one person is allowed in. I just had to wait. Then, they gave me my folder and I asked, 'What do I need to do?' And they told me to go fetch my medication. I asked, 'Am I not going to see the doctor today? I don't understand.' And they said, 'No, just go fetch your medication.' And that was it. It was very difficult. (Participant 2/F/67)

South Africa's vaccine roll-out programme began in February 2021, targeting frontline healthcare workers, followed by an age-based eligibility over the next six months. At the time of interviewing, fourteen of fifteen participants were vaccinated. Most received their vaccine with DCCT, who arranged for an interpreter to accompany them. Several went with an interpreter, but not through DCCT. Among those who received the vaccine, eleven stated they would not have gone if DCCT had not shared information about the vaccine and arranged to have an interpreter present so they could communicate effectively and ask questions:

If I hadn't had an interpreter there, what if I couldn't see my name called and missed my appointment? What if I said yes but didn't know which vaccine I'm getting? What if I had an allergic reaction because they didn't ask the right questions, or I didn't understand correctly so gave the wrong answer? (Participant 15/M/45)

Two participants were vaccinated without an interpreter present. One explained the difficulty navigating the process without an interpreter:

There were no interpreters at the vaccine sites but because I wanted to protect myself, I just went. There was no one to explain the process, it was very difficult for me to understand. Communication would have been smoother with an interpreter but they're so busy and there aren't many. I felt stressed and under pressure. I tried written communication, but it wasn't easy. (Participant 5/M/41)

Discussion

This study focused on the ways in which COVID-19 policies impacted Deaf persons' access to COVID-related information, ability to communicate, and access to and quality of health and social services. The findings demonstrated the overlooked pandemic needs of the Deaf community that warrant urgent public health policy action.

This study found that COVID-19 information was largely sourced through DCCT, the interpreted news, and social networking sites, with few mentions of family members. The lack of COVID-related information available in SASL was emphasised by participants and many expressed their desire to gain more in-depth knowledge about COVID-19. Despite the universal desire for COVID-19 information (Adigun, 2021), Deaf people have less access to information compared to hearing people, which caused feelings of isolation, frustration, and fear. Our findings show that this information isolation is replicated within the home for Deaf people who live with hearing family members, which is consistent with Adigun (2021), whose Deaf/Hoh respondents 'under-rated family members as a source of COVID-related information.' This is largely because hearing family members are often not proficient in the relevant signed language, thus limiting their capacity to share complex information. Linguistic isolation within the home may lead to greater social isolation and the associated mental health consequences during shelter-in-place orders.

Although the limitation of information available to Deaf people is not a new phenomenon, its consequences are magnified during a pandemic, where information is developing more rapidly than ever, and a lack of access to accurate information may be life-threatening. Several participants in this study reported not adhering to protective measures and lockdown mandates as a result of an information deficit, thus increasing both their risk of infection and also the potential legal consequences of not following mandated regulations. A grim example of the latter, two Deaf Ugandans were shot at by authorities for being outside during the mandated curfew; however, they had no access to information regarding the measures in place and thus, were unaware of a curfew mandate (Brennan, 2020). The lack of pandemic-related information

available in SASL highlights how minoritized languages have been disregarded in crisis communications. The provision of public health messaging in one's native language that is both linguistically and culturally accurate increases the support for and adoption of recommended actions (Di Carlo et al., 2022). This was substantiated by participants, who reported improved adherence to COVID-19 policies after receiving information in SASL from DCCT or their Deaf peers. Additionally, our findings provide support for existing literature indicating that older Deaf/Hoh adults may experience a greater degree of information and social isolation during the pandemic (Xu et al., 2021). Less comfort with newer technologies, such as social media, may further limit the sources of information accessible to older Deaf/Hoh adults, highlighting the need for targeted support for this group.

NGOs play a critical role in addressing the lack of support and pandemic information from government. This study demonstrated the notable work of DCCT as a communication platform, source of COVID-19 information, and support system that was essential for the Deaf community. Participants expressed that COVID-related information provided by DCCT was largely the only information in SASL many had access to. To overcome the general inaccessibility of public information, Deaf people often rely on one another as sources of accessible information. This was highlighted by participants who expressed the responsibility they felt to share information with their peers and through the social networks that disseminated information from DCCT, to employees, to the rest of the community.

DCCT was also vital in facilitating vaccination for the Deaf community. Despite recommendations from the WHO to consider PWDs as Stage II priority cases for vaccination, PWDs were not prioritised in South Africa's vaccination strategy. Among a sample of 402 PWDs in South Africa who completed an online survey between July and August 2021, only 10% had received a vaccine, although 75% were willing to be vaccinated (Hart et al., 2021). The proportion of vaccinated participants in this study, 93% (14 of 15 participants), far surpassed the 25% national rate at the time of interviews (October 2021). The high rate of vaccination among participants can likely be attributed to DCCT, who provided accurate, timely vaccine information and facilitated the process of having an interpreter at the vaccine site. The importance of prioritising vaccination for the Deaf community, as one of many vulnerable groups, is illustrated here. High levels of vaccination amongst the Deaf community and amongst those who provide services to the Deaf community would enable easier communication without the barriers of masking and other precautions.

In South Africa, other COVID-19 governmental responses bypassed the Deaf community. Contact tracing, the method of identifying and counselling potential disease cases to prevent disease transmission, relied mainly on telephonic means of communication (Modisenyane et al., 2021). There were no guidelines to inform tracers on how to contact and communicate with a Deaf/Hoh case, preventing them from receiving critical information regarding COVID-19 risk, testing and isolation, and the support resources available, such as the provision of food parcels.

On a community level, NGOs and community networks have come together to support the most vulnerable during the pandemic. Within two months of the national lockdown, over 170

Community Action Networks (CANs), known collectively as Cape Town Together (CTT), emerged across Cape Town as a community-driven response to COVID-19. Each CAN is self-organised by community members and its actions are based on the unique needs of their community but are still able to collaborate with other CANs under the CTT umbrella to share resources, information, and support (van Ryneveld et al., 2022). These mutual aid initiatives provided invaluable support and resources for thousands of people through mask-making and distribution schemes, community kitchens, and temporary accommodations for those experiencing homelessness to name just a few (CAN Writers, 2020). However, these community networks were not entirely inclusive as they neglected to network with DCCT or any other disability persons' organisations (DPOs). These examples demonstrate the missed opportunities for collaboration and inclusion that occurred on both the community and national level.

It is evident from the findings of this study and existing literature that masking and social distancing mandates exacerbated existing communication barriers between Deaf and hearing people. Many Deaf people had to resort to written communication, as masks prevent lip-reading, a commonly used mode of communication when interacting with hearing people. Restrictive social distancing policies and a fear of close contact hindered the effectiveness of written communication. This is a pattern seen globally. For example, Deaf people reported experiencing negative and hostile interactions with hearing people who refused to make concessions for the sake of communication (Ned et al., 2020; Jesus et al., 2021). Communication while accessing basic services, such as social services, public transportation, and police services, also worsened during the pandemic for Deaf people.

Importantly, this study found that masking and social distancing mandates negatively impacted communication amongst Deaf persons. Participants described the internal conflict they experienced between adhering to masking mandates and the ability to communicate in SASL, a conundrum unique to signed languages. During Levels 4 and 5 of the lockdown, when DCCT was closed and social gatherings prohibited, Deaf people, especially those who lived only with hearing people, were deprived of sign-deaf spaces, which are 'networks of social relationships that function to create spaces of shared language, familiarity, sociability, and communality in an often-hostile hearing world' (Heap, 2006). This loss of social cohesion, where collective gathering is the norm, diminished the ability of Deaf persons to communicate and congregate in a culturally normative way, thus limiting their ability to express part of their Deaf identity. While most experienced some degree of social isolation during the pandemic, the modern technology used to maintain remote relationships is often not optimised for signed languages, creating an additional barrier for Deaf people to connect with their community. As a visual language with no written equivalent, Deaf people must rely on written languages to utilise text messaging. However, low literacy amongst the Deaf population limits their ability to communicate effectively through text messaging. Access to video technology is also limited due to the high cost of data.

There is abundant literature regarding healthcare provider's negative attitudes and biases towards PWDs and the consequences this discrimination has on quality of care (Masuku, 2020). The same is true for patient-provider interactions that occur across a language barrier (Shamsi et al., 2020; Lesch et al., 2019). The findings from this study and several others demonstrate that existing discriminatory practices and communication barriers have worsened during the pandemic (Ned et al., 2020).

There was a lack of consideration regarding how COVID-19 policies may impact the experiences of PWDs and linguistic minorities in the health system. The refusal of interpreters, imposition of mask mandates, and the consequential reliance on written communication not only compromised the quality-of-care Deaf patients received, but further infringed on their right to receive health information in their preferred language, as granted in the South African Health Act (61 of 2003), as well as their Constitutional right to access quality health care. This study found positive examples where accommodations, such as allowing an interpreter or removal of a mask, were granted due to an existing relationship and a common understanding of the communication needs of Deaf people among staff. These examples highlight how prioritizing education, communication, and trust to foster relationships can improve the cultural competency of providers and empower Deaf patients in the health system.

Kritzinger et al. (2014) highlights how interpersonal factors such as shyness, insecurity, and passiveness, that stem from a history of exclusion and disempowerment often compound communication barriers in healthcare interactions and further reinforce the negative perceptions that Deaf patients have of the health system. The phenomenon of the 'empty nod' during patient-provider communication, as presented by Xu et al. (2021), whereby many Deaf people often answer 'yes' to questions without a full understanding of what was said was supported by this study. In the absence of interpreters, participants reported leaving consultations still unclear, a violation of their right to informed consent and jeopardising their human dignity and autonomy. However, some advocated for themselves by asking for clarification of unclear written notes, demanding providers remove their masks, and inventing creative solutions to surpass barriers such as writing 'Deaf' on their medical folder. Improved education among healthcare workers and the inclusion of Deaf voices at all levels of governance is critical to ensure policies and practices are inclusive and non-discriminatory and in turn, improve the capacity for self-agency of Deaf people in the health system.

There is little research into the COVID-19 impacts for Deaf people and particularly in LMICs. This study was unique in that it examined how the COVID-19 response measures impacted the fabric of the Deaf community and communication between Deaf people rather than only the Deaf experience within the hearing world.

Participants were recruited because of their connection to DCCT, which limits the range of perspectives and excludes deaf people who do not use SASL and are not a part of the Deaf community, a population which is often more vulnerable than those in the Deaf community. However, non-probability sampling methods are often used for qualitative, exploratory research and thus, were deemed fit for this study. There is an inherent limitation when conducting

research across languages, especially when those languages differ in modality. The use of qualified, professional interpreters that are experienced with research, method triangulation, and rounds of consultation were employed to minimise this limitation. Additionally, DCCT was chosen due to their long-standing relationship with UCT researchers, which has created trust and commonality over the years, empowering those in the Deaf community during the research process.

Conclusion and recommendations

The COVID-19 pandemic has had severe ramifications for PWDs and linguistic minorities and exacerbated existing institutional and societal barriers. These findings demonstrate how the pandemic has both exacerbated existing inequities regarding access to information, health, and social services, as well as created new challenges for Deaf people.

The absence of understandable COVID-19 information for linguistic minorities is a global problem and the information deficit it produces has devastating consequences. This study evidenced how providing information in one's native language through trusted sources and networks can improve behaviour change outcomes. To best promote access to and acceptance of public health messaging, state and local actors and policy leaders should actively engage with Deaf organisations, such as DCCT, to collaborate on the creation and dissemination of COVID-19 communications.

The exclusion of DPOs from Government's COVID-19 disaster management mechanisms likely led to discriminatory policies, which particularly disadvantaged Deaf people when accessing health services. The failure to give effect to the linguistic rights of Deaf people and signed languages violates their Constitutional right to equality, quality health care and, more broadly, to be active citizens in society. Inclusion of Deaf people and organisations at all levels of society along with the integration of Deaf culture awareness and linguistic rights into training and practices in the health system is critical.

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Appendices

Appendix A: Consent Form

Research project: Understanding the impacts of the COVID-19 pandemic response measures on Deaf adults in Cape Town.

HREC number: 198/2021

PI Contact Information: Leslie London; 0214066524

My name is Charlotte Slome, and I would like to invite you to be a part of a research project as part of the Master of Public Health (MPH) programme in the UCT School of Public Health and Family Medicine. I will explain the research process, any risks and benefits, and your rights as a participant so you have all the information before you make your decision.

About the study: The purpose of this study is to get a better understanding of how the COVID-19 pandemic and its response strategies, such as handwashing, masking, social distancing, and lockdown have impacted and been experienced by Deaf adults in Cape Town. You have been invited to participate in this study and share your experience as a Deaf adult during the pandemic. If you agree to participate in the study, you will be asked to give your consent. A printed copy of the consent form will be given to you to keep in either English, isiXhosa, or Afrikaans. The consent process and the interview will be recorded on video. The video recording will help me make sure I am correctly understanding and using what you said. We would also like to keep the video recording for a potential documentary in the future if you are willing but if not, the video will be destroyed after the report is written. If you do not want to be recorded on video, you can sign a printed version of the consent form and an audio recording of the interpreter will be used instead.

Please do not feel pressured to take part in this research study. Even if you agree to participate, you are free to withdraw at any point, even after the interview. If you decide not to participate or withdraw your consent later, it will not result in any consequences.

Research Process: This study will involve an interview that will be around one hour long. A qualified professional SASL interpreter will be present throughout the interview. The interviewer (myself) will begin by asking some demographic questions, such as your age, what area you live in, and job. The next set of questions will be about your experience of COVID-19 response strategies: hand hygiene, masking, social distancing, and lockdown policies. If there are any questions you do not want to answer, you do not have to, you can tell the interpreter to skip that question and we will move on.

You will be given R150 to compensate for your time and travel costs.

Risks and Benefits: There are no expected risks associated with your participation in this study. COVID-19 related risks will be addressed according to global guidelines and standards. You will be given hand sanitiser and a face shield at the start of the interview. The interview site will be properly ventilated and large enough so we can all be seated 2 metres apart. There are no direct benefits associated with your individual participation in this study. However, the study aims to benefit on a community level by providing insight to how the rights of Deaf adults have been threatened throughout the pandemic, which can inform local health interventions to improve access to health services during the pandemic. On a broader level, the findings of this study hope

Appendix B: Confidentiality Agreement for Research Staff

Research project: Understanding the impacts of the COVID-19 pandemic response measures on Deaf adults in Cape Town.

HREC number: 198/2021

PI Contact Information: Leslie London; 0214066524

Position on research staff: _____

The ethical guidelines of this study require that you read and sign this form, signifying that you are willing to enter into a confidentiality agreement with respect to the data collected in this study.

By signing this agreement, I agree to:

1. Keep all the research information shared with me confidential. I will not discuss or share the research information with anyone other than members of the research staff.
2. Abide by my duty to preserve and protect the privacy and confidentiality of each participant.
3. Keep all research information secure while it is in my possession.
4. Not allow any personally identifiable information to which I have access to be accessible from anyone outside the research team.

Name

Place, Time and Date of consent

Name

Place, Time and Date of consent

Appendix C: Interview Schedules

Original:

1. How has the pandemic and its control measures impacted on your livelihood?
 - a. *Difference in income, physical or mental wellbeing, social support, feelings of loneliness*
2. Tell me a bit about how you have experienced the pandemic and its control measures?
 - a. *Have you faced any challenges as a Deaf person that have worsened or improved during the pandemic?*
3. How easy was it to comply with the control measures?
 - a. *Have you had any difficulty complying with any of the control measures? For what reasons?*
 - b. *What do you think influences your ability or willingness to comply with control measures? Such as family/friends attitudes, mask wearing with hearing aids, Covid-fatigue.*
4. Have you experienced any situations where you felt more at risk due to the COVID-19 regulations?
 - a. *How did you react in those situations?*
5. How could the response to the pandemic have been managed differently?
 - a. *For Deaf people specifically?*
 - b. *If you could make the rules, what would you have done differently?*
6. How has your ability to communicate been impacted by COVID-19?
 - a. *In daily activities (e.g. grocery shopping); accessing professional interpreters; using informal interpreters; accessing services and communicating with health workers*
7. Did you access any health or social services (e.g. grants) during the pandemic? If so, what was your experience?
 - a. *Was your ability to access these services different from accessing services before the pandemic?*
 - b. *Did you have access to an interpreter? Professional or informal?*
 - c. *How was the quality of the services?*
8. Who do you tend to rely on for COVID-19 information?
 - a. *What sources do you tend to use for information (social media; TV/radio/newspaper; SMS/WhatsApp groups; in-person conversations)*
 - b. *Do you feel the Government provided sufficient access to COVID-19 related information for Deaf people? Including general information about the virus (transmission, risk, severity, symptoms); What the policies and restrictions are; Where to find information; Where to find testing sites and health services; What support resources and services are available; Information about the vaccines?*

Revised:

1. How has the pandemic impacted on your livelihood? (Probes: Difference in income, physical or mental wellbeing, social support, feelings of loneliness)
2. For each of the response measures, can you tell me a bit about how you have experienced them in general and any experiences you've faced as a Deaf person dealing with these.
3. How easy was it for you to follow and adjust to the control measures? (Probes: Have you had any difficulty complying with any of the control measures? For what reasons?; What do you think influences your ability or willingness to follow with control measures? Such as family/friends attitudes, mask wearing with hearing aids, COVID-fatigue)
4. Have you experienced any situations where you felt more at risk as a Deaf person due to the COVID19 regulations? (Probes: How did you react in those situations? How did that make you feel?)
5. How do you think the response to the pandemic from the Government have been managed differently? (Probes: For Deaf people specifically?; If you could make the rules, what would you have done differently?)
6. How has your ability to communicate been impacted by COVID-19? (Probes: In daily activities (e.g. grocery shopping); booking professional interpreters; using friends/family as interpreters; accessing services and communicating with health workers)
7. Did you access any health or social services during the pandemic? If so, what was your experience? (Probes: Was your ability to access these services different from accessing services before the pandemic?; Did you have access to an interpreter? Professional or informal?; How was the quality of the services?)
8. Who do you tend to rely on for COVID-19 information?
 - a. What sources do you tend to use for information (social media; TV/radio/newspaper; SMS/WhatsApp groups; in-person conversations)
 - b. Do you feel the Government provided enough access to COVID-19 related information for Deaf people? Including general information about the virus (transmission, risk, severity, symptoms); What the policies and restrictions are; Where to find information; Where to find testing sites and health services; What support resources and services are available; Information about the vaccines?
9. Do you have anything else you'd like to add about your experiences of the pandemic control measures or the pandemic in general?

Appendix D: Standard Operating Procedure (SOP)

SOP for Conducting Face-to-Face Interviews with Research Participants in the study
Understanding the impacts of the COVID-19 pandemic response measures on Deaf adults in
Cape Town.

During the initial stages of the COVID-19 lockdown, it was not possible nor was it safe to conduct face-to-face interviews. However, with the recent move to Level 1 and the continual easing of restrictions, conducting face-to-face interviews should now be deemed appropriate in the context of this study, as it is believed necessary for the collection of good quality data. In person data collection will strictly adhere to and enforce all safety precautions in line with national guidelines.

Conditions for conducting face-to-face interviews that must be met:

- i. Potential participant must understand and acknowledge the possible risks associated with travelling to and from the interview site and with the interview itself.
- ii. The interview site can be controlled by the research team and is not dependent on third party behaviour.
- iii. The interview site must meet national safety guidelines
 - a. Has the capacity for natural ventilation with fresh air – at least two windows or doors can be open to allow for air flow.
 - b. The physical site is large enough to allow for at least 2 metres between all parties.
 - c. All frequently touched surfaces can be sanitised before and after each interview.
 - d. Access to the venue does not require any party to pass through a crowded area (e.g. a queue).
- iv. Interviewer adheres to wearing a face mask; the participant and interpreter adhere to wearing a face shield.
- v. All parties (interviewer, interpreter, and participant) adhere hygiene and physical distancing preventive measures.
- vi. The interviewer will be trained on safety protocols pertinent to COVID-19 including, sanitising, PPE, and the safe disposal of contaminated materials. Training materials from accredited websites will be used for this purpose.
- vii. Provision of PPE and materials for hand and surface hygiene
 - a. All participants will be provided a face shield, mask, and pocket hand sanitiser prior to entering the interview site.
 - b. If running water is available at the interview site, soap and disposable paper towels will be provided as an additional safety measure.
 - c. The interviewer will be responsible for the sanitising of all surfaces with the appropriate material (sanitising solution and paper towel) and the proper disposal of used paper towels.

Procedure for selection of parties:

Interviewer

- i. The interviewer will be stratified for risk category for COVID-19 infection using the Provincial Health Department Circular H77 (Screening Tool A, see Appendix D).

Responses will be self-reported and confirmed by Supervisor Leslie London or Myrna Van Pinxteren.

- ii. The interviewer will undergo self-screening the day before and the morning of each interview (*Screening Tool B*, see Appendix D).
- iii. In the event that the interviewer responds ‘yes’ to any of the screening questions, they will:
 - a. Inform Supervisors, interpreter, and participant of the situation. The interview will be cancelled and rescheduling will occur.
 - b. Follow the steps outlined in Appendix E to determine if they need to get tested for COVID-19.
 - c. If the interviewer tests positive or is advised to consider themselves as a COVID-19 case, they will complete the mandatory self-isolation period of at least 14 days starting from the positive test or first day of symptoms, as per guidelines by the National Institute for Communicable Diseases. All interviews scheduled during that time will be cancelled and rescheduled.
 - d. Interviews will only resume once the interviewer has been symptom free for at least 3 days.

Interpreters

- i. Interpreters will be stratified for risk category for COVID-19 infection using the Provincial Health Department Circular H77 (*Screening Tool A*, see Appendix E). Responses will be self-reported and confirmed by the interviewer and/or Supervisors Leslie London and Myrna Van Pinxteren. Only those considered low risk will be selected.
- ii. Interpreters will undergo self-screening the day before and the morning of each interview (*Screening Tool B*, see Appendix E).
- iii. In the event that the interpreter responds ‘yes’ to any of the screening questions, they will:
 - a. Inform the interviewer, who will then inform the participant of the situation.
 - b. Follow the steps outlined in Appendix E.
- iv. If another interpreter is not available, the interview will be rescheduled. A replacement interpreter will be sought out for interviews that are scheduled while the infected interpreter is in self-quarantine.

Interviewees

- i. All participants will be stratified for risk category for COVID-19 infection using the Provincial Health Department Circular H77 (*Screening Tool A*, see Appendix E). Only those considered low risk will be selected to participate.
- ii. All interviewees will be required to undergo COVID-19 symptom screening (*Screening Tool B*, see Appendix E).
- iii. Interviewees who tested positive for COVID-19 before being interviewed will need to have completed the mandatory self-isolation for at least 14 days after testing positive or after first displaying COVID-19 symptoms (as per guidelines by the National Institute for Communicable Diseases).

- iv. Interviewees who were in quarantine because of a close contact with a patient with COVID-19 but who have completed their quarantine of 14 days (as per guidelines by the National Institute for Communicable Diseases) may be interviewed.
- v. Interviewees who are being considered for an interview after quarantine as a close contact, do not require a medical certificate to be interviewed as long as they have completed their full quarantine period without symptoms.

Procedure for COVID-19 screening prior to the interview:

- i. The interviewer and interpreter will self-administer the screening tool (*Screening Tool B*, see Appendix E) the day before each and the morning of each scheduled interview.
- ii. The interviewer will contact the participant the day before their scheduled interview via WhatsApp or SMS to complete the screening (*Screening Tool B*, see Appendix E).
- iii. If the participant declines the screening, does not fully answer, or responds ‘yes’ to any of the questions, the interview will be cancelled.
 - a. If the participant responds ‘yes’ to any of the questions, the interviewer will explain that the respondent may be experiencing COVID-19 symptoms and will advise them to follow the steps outlined in the provided pamphlet (see Appendix F).
- iv. For those who respond ‘no’ to all screening questions, the interview will be confirmed with the participant.
- v. The participant will then be informed of the following
 - a. They must wear a mask upon entering the interview site where they will be given a face shield should they choose to use it instead for the purposes of grammatical accuracy. The interpreter will wear a face shield as to allow for full use of the language. The interviewer will wear a mask throughout the duration of the interview.
 - b. They will be screened again upon arrival to the study site.
 - c. Regardless of whether the interview ultimately takes place, they will receive a stipend of R150 to cover any transport costs associated with travel to and from the interview site.

Procedure for interview:

- i. The following conditions will be ensured at the study site
 - a. Appropriate ventilation – windows and/or doors will be opened to enhance airflow. If needed, a fan will be used to assist circulation of fresh air.
 - b. Chairs will be placed 2 metres apart to ensure physical distancing.
 - c. All parties will be required to use the provided hand sanitiser and wear a mask properly upon entering the study site.
 - d. All surfaces will be properly sanitised using a sanitising solution of at least 70% alcohol before and after each interview.
- ii. Prior to starting the interview process, all parties will agree to adhere to the following

- a. Respect and follow all outlined safety precautions for the duration of the interview.
 - b. If one touches a surface or object in the room that has not been sanitised, the provided hand sanitiser must be used before touching anything else.
 - c. One must cough or sneeze only into their elbow, preferably facing away from others.
- iii. At the end of the interview
- a. All parties must sanitise their hands and wear a mask.
 - b. The interviewee will be reminded that if they start to feel any COVID-19 related symptoms they should follow the steps outlined in the provided pamphlet.

Appendix E: COVID-19 Screening Tools

Screening Tool A, the Provincial Health Department Circular H77, will be used when recruiting potential participants to assess their level of risk for contracting and having severe COVID-19 illness. If the candidate answers ‘yes’ to any of the below questions, they will be considered high risk and will be excluded from the study. Interviewer and interpreters will self-administer the screening tool to determine their eligibility.

1. Are you over 60 years of age? (yes/no)
2. Do you have any of the following illnesses? Chronic lung problems such as, moderate to severe asthma, previous complicated TB, etc.; serious heart conditions; cancer or any diseases compromising your immune system including diabetes, renal hypertension, or liver disease. (yes/no)
3. Are you more than 28 weeks pregnant? (yes/no)

Those that respond ‘no’ to the above questions will have the opportunity to participate in the study. Participants and interpreters will be told to inform the interviewer or any member of the research staff if they think they are experiencing COVID-19 symptoms at any time leading up to their scheduled interview.

Screening Tool B will be administered prior to the interview in SASL by the interpreter to ensure that the participant fully understood and correctly answered all the questions. If the participant realises that they may be infected, their interview will be cancelled and they will be referred to the information in Appendix E.

The interviewer and interpreter will self-administer the screening tool the day before and the morning of each interview.

1. Do you have a fever? This can include feeling very hot or cold, excessive sweating or shivering, and a forehead that is hot to the touch. (yes/no)
2. Do you have a cough that started recently? (yes/no)
3. Do you have a sore throat or pain when swallowing that started recently? (yes/no)
4. Do you have difficulty breathing or excessive breathlessness that started recently? (yes/no)
5. Have you noticed any recent changes in your ability to smell or taste things? (yes/no)
6. Have you recently been in close contact with someone confirmed to be infected with COVID-19? (yes/no/not sure)

Appendix F: COVID-19 Information pamphlet

The following information will be sent to recruited participants via WhatsApp or SMS. A printed version will be given to participants at the interview. English, isiXhosa, and Afrikaans versions will be available.

What to do if you have COVID-19 symptoms?

Your responses to the screening tool indicate that you may be experiencing COVID-19 symptoms. Please follow the steps below.

1. Contact the Provincial Hotline on 021 928 4102 to speak to a health professional about what you should do. The health professional will be able to determine if you need to be tested, depending on your age and whether you have underlying illnesses that put you at risk of developing severe COVID-19.
2. Until you have received medical advice you should self-quarantine at home to avoid spreading the virus to others. You should also take extra safety precautions including hand hygiene, sanitising, and mask wearing.
3. Seek more information
 - a. National hotline: 0800 029 999
 - b. Toll-free hotline: 080 928 4102
 - c. WhatsApp “Hi” to 0600 123 456 to get more information
 - d. <https://knowledgetranslation.co.za/resources/COVID-19-public-resources/>



Source: https://coronavirus.westerncape.gov.za/files/atoms/files/COVID-19_Cape-Town-winter-2020_English_2020-07-22.pdf



Appendix G: HREC Approval Letter



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

25 June 2021

HREC REF: 198/2021

Prof L London

School of Public Health & Family Medicine
Falmouth Building-FHS
Email: leslie.london@uct.ac.za
Student: slmcha008@myuct.ac.za

Dear Prof London

PROJECT TITLE: UNDERSTANDING THE IMPACTS OF THE COVID-19 PANDEMIC RESPONSE MEASURES ON DEAF ADULTS IN CAPE TOWN (MASTERS CANDIDATE: MS C SLOME)

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020 & 06 July 2020.

Approval is granted for one year until the 30 June 2022.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Charlotte Slome will also be involved in this study.

Please quote the HREC REF 198/2021 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

HREC/REF 198/2021sa

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix H: Journal Submission Guidelines

Journal: Disability and Society

Preparing Your Paper

Article

- Should be written with the following elements in the following order: title page; abstract; keywords; points of interest; main text introduction, research process, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should meet a minimum word count of 6000 words and be no more than 8000 words (excluding references).
- Should contain an unstructured abstract of 150 words.
- Should contain [Points of Interest](#) 100 to 150 words (maximum) describing in plain English the importance of your work for lay readers in 4 or 5 bullet points.
- Between 2 and 6 **keywords**. Read [making your article more discoverable](#), including information on choosing a title and search engine optimization.
- Footnotes are discouraged for this journal because they disrupt the experience of following your paper for those using screen readers. Essential information must be included in the main body of the text.
- Tables and Figures must be presented with the interests of those using screen readers in mind.

Current Issues

Guidelines for the Current Issues Section of the journal

The Current Issues section is ideally suited to articles which seek to raise the voices of those who are seldom heard in academic journals. We welcome articles which air controversies and contentions and which stimulate discussion and debate. If you wish to submit to this section please include one sentence in a covering letter telling us why your submission is current; 'This is a Current Issue because ...'

Please select [here](#) to view full guidelines for Current Issue papers.

All papers must be uploaded as a Current Issue submission in the ScholarOne Manuscripts system.

Breakthrough Scholars

Guidelines for the Breakthrough Section of the journal

From 2019 we are delighted to offer a Free to Access BreakThrough Scholars section in the journal to enable new graduates a powerful and important opportunity to showcase their work.

Full information on this section can be found [here](#).

Language Policy

It is essential that all submissions to Disability & Society uphold and demonstrate an awareness of the journal's language policy. Up to date guidance for authors can be found [here](#).

Style Guidelines

Please refer to these [quick style guidelines](#) when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use single quotation marks, except where ‘a quotation is “within” a quotation’. Please note that long quotations should be indented without quotation marks.

Formatting and Templates

Papers may be submitted in Word or LaTeX formats. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

[Word templates](#) are available for this journal. Please save the template to your hard drive, ready for use.

A [LaTeX template](#) is available for this journal. Please save the LaTeX template to your hard drive and open it, ready for use, by clicking on the icon in Windows Explorer.

If you are not able to use the template via the links (or if you have any other template queries) please contact us [here](#).

References

Please use this [reference guide](#) when preparing your paper.

An [EndNote output style](#) is also available to assist you.

Checklist: What to Include

1. **Author details.** Please ensure all listed authors meet the [Taylor & Francis authorship criteria](#). All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCIDiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors’ affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. [Read more on authorship](#).
2. **Graphical abstract** (optional). This is an image to give readers a clear idea of the content of your article. It should be a maximum width of 525 pixels. If your image is narrower than 525 pixels, please place it on a white background 525 pixels wide to ensure the dimensions are maintained. Save the graphical abstract as a .jpg, .png, or .gif. Please do not embed it in the manuscript file but save it as a separate file, labelled GraphicalAbstract1.
3. You can opt to include a **video abstract** with your article. [Find out how these can help your work reach a wider audience, and what to think about when filming](#).
4. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:

For single agency grants

This work was supported by the [Funding Agency] under Grant [number xxxx].

For multiple agency grants

This work was supported by the [Funding Agency <] under Grant [number xxxx]; [Funding Agency >] under Grant [number xxxx]; and [Funding Agency &] under Grant [number xxxx].

5. **Disclosure statement.** This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The authors report there are no competing interests to declare.* [Further guidance on what is a conflict of interest and how to disclose it.](#)
6. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). [Templates](#) are also available to support authors.
7. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a [recognized data repository](#) prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
8. **Geolocation information.** Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper's study area accurately in JournalMap's geographic literature database and make your article more discoverable to others. [More information.](#)
9. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about [supplemental material and how to submit it with your article.](#)
10. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, GIF, or Microsoft Word (DOC or DOCX). For information relating to other file types, please consult our [Submission of electronic artwork](#) document.
11. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
12. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about [mathematical symbols and equations.](#)
13. **Units.** Please use [SI units](#) (non-italicized).