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Health information and education needs for youth with complex communication needs during the Covid-19 pandemic: rehabilitation professionals' perspectives

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ABSTRACT

Purpose: The worldwide Covid-19 pandemic has highlighted inequities faced by persons with complex communication needs (CCN) in accessing health information and education. This study reports on the perspectives of South African rehabilitation professionals regarding access to health information and education for youth with CCN.

Materials and methods: Two asynchronous online written focus groups were conducted with 15 rehabilitation professionals. Participants' contributions were thematically analysed.

Results: Participants reported that youth with CCN faced a variety of challenges when accessing health information, related, amongst others, to the format and quality of the information. Participants reported on strategies they had successfully used to support comprehension of health information and the youth's communication during healthcare encounters. Participants suggested various Covid-19-related and general health topics of value to youth, as well as a variety of multimodal and multilingual presentation formats to make health information accessible. This information was used in the development of accessible health information resources that are now freely available on the authors' institutional website.

Conclusions: The results confirmed that there is an urgent need to make accessible health information available in order to include South Africans with CCN in health services during the pandemic and beyond.

➤ **IMPLICATIONS FOR REHABILITATION**

- Health information and education (including information and education provided with respect to the Covid-19 pandemic) has often not been accessible to youth with complex communication needs (CCN).
- South African rehabilitation professionals reported on a variety of challenges that youth with CCN face when attempting to access health information and education, but also reported on strategies that had helped to support them in this.
- They also highlighted Covid-19-related and general health topics that would be of value to youth, and suggested a variety of information formats and strategies to make health information more accessible.
- This information can assist in the design of appropriate and accessible health information resources for youth with CCN and other individuals who experience communication challenges.

Introduction

The advent of the Covid-19 pandemic worldwide has increased health risks for all people, and the timely and effective release and distribution of accessible, credible, and reliable health information has played a big role in effective health management during the pandemic [1]. Furthermore, management has included interactions with healthcare staff in the process of screening, diagnosing, treating, and vaccinating against the disease. However, concerns have been raised around the world that persons with disabilities have been side-lined in the response to the pandemic [2–5]. Amongst others, relevant health information and public health messaging has not always been accessible to persons at risk for communication challenges (e.g., those with

complex communication needs or CCN, and those who face language barriers) due to the complexity or format of the information. Disability-specific information (e.g., regarding additional risks, continuation of and access to disability-related health services) has not always been made available, and communication barriers that may be encountered in face-to-face interactions with healthcare providers (which may be exacerbated by, for example, the wearing of masks) have not always been given due consideration [6].

Similar observations have been made in the South African context [7,8], where the pandemic has in many ways increased health inequities for people with disabilities, not least because of a lack of accessible health information. South Africa ratified the

Convention on the Rights of Persons with Disabilities (CRPD) [9] in 2007, where the right to quality healthcare without discrimination for persons with disabilities is enshrined in Article 25. The South African Constitution [10] similarly confirms the right of all persons in the country to access healthcare. This right is further given effect by the National Health Act [11]. The provision of accessible health information in appropriate language and in a format aligned to patients' literacy levels is specifically mentioned in the Act (Section 6[2]). However, for many patients, including those with CCN and those from minority and lower status language backgrounds, this remains an unattained ideal [12,13]. Similarly, the Integrated School Health Policy [14] instituted nationally in the country in 2012, mandates health education programmes for students in all schools, including schools for learners with special educational needs. However, a recent study found that compliance with this policy is poor [15].

Augmentative and alternative communication (AAC) strategies have been effectively employed to address communication challenges experienced by persons with CCN and those with other communication-related risk factors within healthcare encounters. A recent systematised review [16] found that AAC strategies (e.g., communication boards, visual schedules, and key word signing) and alternative formats of health information (e.g., via illustrated stories or in video format) have been effectively employed to reduce communication challenges for persons with a variety of communication-related risk factors in a variety of healthcare settings, such as emergency medical services, intensive care settings, and the general healthcare setting [17]. In another review, it was found that visual support material can make health information more accessible to persons with low literacy levels [18].

It has been noted that the provision of AAC systems and visual communication supports in itself is typically not sufficient to address communication challenges in healthcare settings [19]. Healthcare providers themselves play an important role in mediating access to the healthcare environment and access to health information for persons with CCN. Their attitudes and expectations of persons with CCN can influence the success with which information is exchanged [20]. Training healthcare providers to use communication strategies with persons with CCN can increase their knowledge, self-efficacy, and skill in communicating with them [21,22].

In order to address the lack of accessible health information material and the lack of resources to support communication around Covid-19, a research project was undertaken with the aim of co-developing accessible health education and communication support materials for and with youth with CCN for use in the Covid-19 pandemic in South Africa. According to the National Youth Commission Act (No. 19 of 1996) of South Africa [23], youth refers to persons aged 14–35. The research project was conducted in three phases, including (1) a preparation phase during which relevant information was gathered from different stakeholder groups, (2) a co-development phase, as described in Dada et al. [24], and (3) a resource dissemination phase, with materials made available on the authors' institutional website (https://www.up.ac.za/centre-for-augmentative-alternative-communication/article/2938080/co-designing-health-education-materials-). In the first phase (preparation), a situation and needs analysis regarding access to health information for youth with CCN was conducted with three stakeholder groups (youth with CCN, caregivers of youth and children with CCN, and rehabilitation professionals). This paper reports on the views of rehabilitation professionals experienced in providing support to youth with CCN during the pandemic, as obtained during phase 1. We included them in the needs analysis as they have an overall mandate to support persons with disabilities to achieve optimal quality of life, and this would include supporting youth with CCN to participate in their own healthcare. We therefore aimed to gain their perspectives regarding the challenges, current strategies, and needs around accessing to health information experienced by youth with CCN in South Africa.

Materials and methods

The study was approved by the Reserch Ethics Committee of Humanities, Universtity of Pretoria (reference number HUM027/0820). The larger study comprised of a participatory action research project using multiple qualitative methods with the overall aim of designing and disseminating stakeholder co-produced health information and education materials. The current study, as part of phase 1, was conducted using a qualitative community-engaged approach. According to Padgett [25], community-engaged qualitative research aims to involve community members in gaining an understanding of a specific situation or phenomenon, as a first step before engaging in action to address the situation. Two asynchronous written focus groups were conducted with a total of 15 rehabilitation professionals. Asynchronous text-based focus groups allow participants to respond in writing on a discussion board within a set time frame, but the exact time when they respond is not set and need not be synchronised with other participants [26,27]. The online asynchronous format was chosen as it allowed participants from different geographical areas to participate, and allowed for flexible timing of engagement that was compatible with the busy schedules of the rehabilitation professionals [28,29]. Data collection was also not impacted by lockdown restrictions which discouraged face to face contact. Asynchronous formats have furthermore been postulated to allow more time for reflection on the questions, possibly leading to deeper engagement [29].

Participants

Participants were purposefully selected from the professional network of rehabilitation professionals who provide AAC intervention. This network, held at the authors' institution, comprised of alumni from the various AAC-related academic programmes offered as well as professionals who had attended previous AAC trainings or AAC consultations at the authors' institution. Participants were chosen as they were registered with the Health Professional Council of South Africa and were offering support to youth in need of AAC during the Covid-19 pandemic. An attempt was initially made to include both rehabilitation professionals (speech language therapists (SLTs), occupational therapists (OTs), and physiotherapists (PTs)) who worked in a variety of settings (e.g., public and private hospital setting, non-government organisation, rehabilitation clinic, and private practice) as well as educators working in public schools for learners with disabilities and non-government organisations with a focus on youth with disabilities, in order to obtain a variety of perspectives. A total of 28 professionals were contacted via email, inviting them to take part in the study. A detailed information letter with a link to an online consent form were included in the email. The information letter explained the purpose of the study, the rights of the participants, and the risks and benefits of participation.

A total of 15 rehabilitation professionals replied and consented to take part in the study. None of the four educators approached consented. This may have been coincidental or a reflection of their workload and inability to commit at the time. There were no

Table 1. Participant demographics.

Variable	n	Percentage
Profession		
OT	3	20%
PT	1	7%
SLT	11	73%
Work setting[a]		
NGO	4	27%
Public hospital	3	20%
Private practice	2	13%
Higher education	2	13%
Assistive technology provider	2	13%
Public school	1	7%
Private rehabilitation service	1	7%
Private hospital	1	7%
Populations served		
Mainly adults	4	27%
Mainly children	4	27%
Both	7	47%
AAC methods and strategies		
Various[b]	11	73%
Mainly low tech	3	20%
Mainly high tech	1	7%

[a]One rehabilitation professional worked in more than one setting.
[b]This included unaided and aided [low, mid, and high tech].

obvious systematic differences between the rehabilitation professionals who consented and those who did not. It did seem that those who consented tended to be somewhat more junior. In one case, the person originally contacted (who was in a more senior, managerial position) suggested that two more junior colleagues be contacted, who then participated. To contain group size and allow some flexibility regarding dates, two focus groups were conducted. Participants were assigned based on preference and in a way that ensured that groups were roughly equal in numbers. Three OTs, one PT, and four SLTs took part in the first focus group, and seven SLTs took part in the second focus group. Participants had an average of 17.3 years of experience of working with persons with disabilities (range: 2–55) and an average of 8.7 years of experience working with persons in need of AAC (range: 1–33). Further demographic information is provided in Table 1.

Procedure

The online asynchronous text-based focus groups were hosted on a private discussion board using the online learning system, Blackboard Learn (a product of Blackboard Inc., Washington, DC, www.blackboard.com) on a secure server of the authors' institution. For each focus group, the asynchronous discussion was open for three days. In preparation, each participant received a unique password as well as detailed instructions via email explaining how to access the discussion board, encouraging daily participation and emphasising that every experience and view shared would be valued, even if these differed between participants. Participants had the opportunity to test their access and familiarise themselves with the discussion board prior to the commencement of the discussion.

In the discussion board, a "welcome and facilitation" thread was created. The message posted here welcomed the participants, restated the aims of the focus group and briefly introduced facilitators and all participants. The process of engagement was explained, including an expectation regarding frequency of posting, as well as the request to maintain confidentiality. In a further thread, participants were requested to introduce themselves and

provide some context regarding their work place, their caseload, and the type of support they provided to persons and particularly youth in need of AAC. A discussion thread was then created for each of four main questions, namely

1. Can you describe the challenges that youth (adolescents and young adults) whom you work with have experienced in accessing health information and education? This could include challenges you have experienced when providing such information/education, or challenges you have observed when youth seek or receive information from other sources, like the internet or from medical institutions and health-care providers.
2. What strategies have you found to be helpful when conveying health information to or conducting health education with youth with communication disabilities?
3. What are some of the topics that need to be covered in health education programmes for youth with communication disabilities broadly and also specifically related to Covid-19?
4. What resources are required in your setting to assist youth with communication disabilities to access information about Covid-19 and other health issues?

Participants were asked to post on each question at least twice, with a 24-h gap between the first and second posting, to allow them to follow up on any questions others may have had regarding their first post. They were able to read and respond to the posts of other participants. They could edit their own posts and were encouraged to do so throughout the three days as a limited form of member checking. The first and second authors acted as facilitators, positively acknowledging contributions, checking understanding where necessary, summarising points made and posing written follow-up questions. They closed the discussion after three days and downloaded the participants' postings for each question, converting it to a word document.

The facilitators were academics, qualified as SLTs with postgraduate qualifications in AAC. They had been working in the field of AAC for 23 and 24 years respectively, primarily in an academic capacity. They had directly supervised and/or taught six of the participants during their postgraduate studies. The facilitators were aware of the possible power differential between themselves and some participants caused by these factors. Most participants ($n = 14$) worked primarily or exclusively in practice, and many had a wealth of practical experience. Neither of the two authors had any prolonged practical experience in making heath education and information material accessible to youth with CCN. Participants therefore had more expertise in the topic at hand, and facilitators sought to affirm and acknowledge this throughout the discussion.

Data analysis

The downloaded text files were uploaded into Atlas-ti. Thematic analysis using a codebook approach [30] was used to analyse the data. According to Braun and Clarke [30], this approach is well-suited to applied research that is intended to guide practice. A combination of inductive and deductive coding was used. The overall a priori themes were aligned to the four questions, namely of (1) challenges that youth with CCN experienced in obtaining health information and education, (2) strategies that professionals had found helpful in the past to assist youth with CCN to gain access to health education and information, (3) health topics of importance to youth with CCN, and (4) resources and strategies needed to improve health education and information access for

youth with CCN. However, the actual codes and subthemes were identified inductively from the data. The focus of coding was on semantic or explicit meanings rather than attempting to code latent meanings. The first author familiarised herself with the data by reading through all the postings from both groups on all questions, provisionally annotating the documents with notes. She then coded all the data that seemed relevant to the overall research aim in a first cycle of coding [31], dividing the text into segments in the process. Next, she grouped the codes into categories (subthemes) and aligned them with the four overarching *a priori* themes aligned to the four questions. A provisional codebook was developed. The third author then checked the coding of all the text files, making suggestions for changes. The coding was refined and updated in numerous rounds of reflective discussion between the two authors until consensus on the codebook and coding was reached, thereby increasing trustworthiness.

Findings

A total of 63 different codes were identified, and these were applied 465 times to the identified text segments. Codes were grouped into 13 subthemes, with two to five subthemes associated with each of the four main themes. The subthemes identified under each of the four *a priori* themes as well as examples of codes associate with each subtheme are presented in Table 2.

The findings are also presented in the sections following, under each of the four *a priori* themes. Participants are identified by profession and numbers 1–15.

Challenges

When discussing the challenges faced by youth with CCN in relation to obtaining health information and education, the rehabilitation professionals spoke about challenges related to (1) the information itself, (2) the healthcare provider, (3) the youth and their families, (4) the healthcare encounter, and (5) a lack of resources.

In the first instance, they described challenges related to the information itself. Youth were reported to access information from a variety of sources, including the internet, the media, by asking family and friends, and in verbal and written format during healthcare encounters and/or healthcare education sessions. A preference for internet sources was mentioned. All sources were

Table 2. Summary of themes, subthemes, and examples of codes.

Theme	Subtheme	Examples of codes
Challenges	Information	Quality of information is questionable
		Complex and highly abstract
		Lack of alternative modalities
		Not accessible – youth had no access to data or devices
	Healthcare provider [HCP]	Attitude and stigma
		Lack of knowledge/awareness
		Poor practices and lack of teamwork
	Youth with CCN and their families	Pandemic and lockdown-related disengagement and stress
		Disempowerment
		Limited skills
	Healthcare encounter	Masks and safety gear impede on interactions
		Lack of privacy
		Stressful and pressured (limited time, noise)
	Resource-related	Not used or not available during healthcare encounters
		Youth does not have access or does not use resources (e.g., communication board)
Strategies that have been helpful	Supports for communication and engagement	Support engagement
		Support comprehension: concretise information
		Support comprehension: adapt presentation
		Support comprehension: visual aids and additional modalities
		Support expression
	Dissemination	Electronic dissemination
		Hard copy and face-to-face dissemination
		Guide youth to relevant and credible information sources
	Other	Instructions to communication partners
		Teaming and training
Health topics to be covered	Covid-19	Coping and mental health
		Disease management and diagnostic procedures
		Disease prevention
		Lockdown rules, management, risk management
		Understanding the disease
	General	Diagnoses and conditions
		Health system information
		Healthy living and health management
		Patient rights, empowerment, communication
Resources and strategies needed	Information: characteristics, formats, and presentation	Characteristics
		Visual format
		Auditory format
		Videos
		Information in different languages (including sign language)
	For specific contexts	Health encounters and group/individual health education
		Public health information: platforms and formats
		For use in the home
	Other	Training and empowerment of youth with CCN
		Training and guidance for HCP and support persons
		Technology and data resources
		Policy and legislative support for communication access

described as problematic to some extent. Participants described the amount of information provided in healthcare encounters and the internet as overwhelming, and the nature of it as highly complex and abstract.

> A further barrier is the language used in some of the printed young adult health education materials. Often (the) … technical or medical terminology or language used could not be understood by a young adult with limited intellectual ability. [OT1]

In addition, information was also often only available in one modality (e.g., only transferred verbally or only given in written format), without the option of alternative formats such as supporting diagrams or other visuals. Information was sometimes inaccurate, misleading, not appropriate, or ambiguous, especially when obtained from internet sources that had no credibility. International sources were described as "not specific to South Africa" (SLT7). Electronic information or health education opportunities were not available to youth who had no access to data or electronic devices. Furthermore, access to health information for youth with CCN seemed not to be a priority in intervention or school curricula.

> There is currently no curriculum for this (health education) in the school curriculum for special schools. [SLT2]

Second, participants spoke about healthcare provider-related challenges. Participants specifically referred to medical doctors, nurses, but also allied health professionals such as psychologists and therapists. A lack of knowledge and awareness was mentioned most frequently.

> In addition, I think many healthcare professionals lack the knowledge to understand the capabilities of individuals with communication disabilities and as a result assume that they will not be able to understand them. [SLT3]

Poor practices, like rushing through information or providing it only to family members instead of to youth themselves, were highlighted.

> They (healthcare providers) do not try to give them the information or prefer to give the relevant information to family members. [SLT3]

In addition, attitude and stigma were mentioned. For example, some healthcare providers seemed to believe that youth with CCN would not be sexually active, and therefore did not provide information around sexual health. A final challenge relating to healthcare providers was that high staff turnover in hospitals made it hard to train staff in using more appropriate methods of communication.

Third, there were challenges related to the youth and their families. Participants noted a high level of pandemic-related disengagement and stress, making engagement in health education programs difficult.

> Families have really experienced COVID fatigue and inertia with a lot decreased motivation for (using) even more simple devices, programs and exercises. This is getting progressively worse with time and social isolation. It is compounded by a high level of anxiety in families that their children and young people will get sick. [PT4]

Language, communication, and literacy-related challenges were also noted, as well as a lack of skills in searching the internet and distinguishing real and fake information. Finally, rehabilitation professionals perceived that a lack of empowerment may cause youth to refrain from asking questions and seeking out information in a healthcare encounter.

> The patients were initially very reluctant to ask questions and seek clarity out of fear and/or shyness. [SLT5]

Within healthcare encounters (fourth subtheme), the need to wear masks and other safety gear was reported to affect communication between health care providers and youth with CCN. The conditions under which healthcare encounters took place were often not ideal, with short appointment times under stressful conditions due to understaffed and overburdened health facilities. A lack of privacy also compounded the challenges.

> Just being told in a stressful situation where there is much else to absorb at the same time, does not facilitate comprehension. It doesn't allow for engagement, discussion or communication about the issue – often where most true comprehension occurs. [OT6]

Lastly, limited availability and limited use of resources both by rehabilitation professionals and youth themselves were also mentioned.

> Our SLT department developed low tech communication boards to be used in the tents (set up for Covid-19 protocols) and wards in an attempt to facilitate improved communication with those patients with impairments, however, adherence to consistent use was still a challenge. [SLT7]

Strategies that had been helpful

The strategies highlighted as helpful by the participants were grouped under the themes "support for communication and engagement," "dissemination strategies", and "other." Participants provided a lot of detail about the strategies and materials they had used to facilitate engagement and communication with youth with CCN to improve their access to health education and information. These strategies were broadly grouped into those that supported comprehension, those that supported expression, and those that supported engagement with some overlap amongst these subthemes.

In an effort to enhance comprehension of health information, participants mentioned their efforts to concretise the information, to adapt the way information was presented and to employ visual aids and other additional modalities.

> Making social distancing, masks, coughing in mask and elbow concrete using a white board, demonstration, and social stories. [SLT8]

> Breaking it (the information) down into small conceptual units and symbolising the key concepts: Coronavirus is a sickness – Coronavirus is spreading around the whole world – We can help to stop the Coronavirus – We must wear masks – Masks stop the Coronavirus getting into me. [OT6]

> Providing augmented input, be it a short written summary or pamphlet with keywords and/or visuals whilst relaying the necessary health information verbally, can really decrease anxiety/misunderstandings when the patient processes the information later. [SLT9]

> I use social stories and visual schedules as primary tools for sharing new information as well as adapting information about health and education with the young adults and youth I work with, especially students who are autistic. For many of the youth and young adults that I work with, adapting to new and unfamiliar procedures may be stressful for them, and the use of social stories accompanied by visuals to support the story have been helpful. [SLT7]

To facilitate expression, participants ensured that youth had the relevant picture vocabulary available to them on their devices, or designed additional paper-based materials ahead of healthcare encounters.

> … preparing teens who required surgery by preparing paper-based resources for use in hospital, these were designed with their input and also included instructions for whomever could possibly communicate with them in hospital …. [OT1]

Having the right vocabulary available and using strategies like Talking Mats™ to facilitate discussions helped to increase engagement during a healthcare encounter.

> … and in addition, we used the Talking Mat(s) strategy … to facilitate the discussion as well as a board with additional relevant pictures. [OT1]

Other interactive activities such as role play and games were also used to facilitate engagement during healthcare education opportunities.

Participants also mentioned the importance of disseminating this information via different channels and media. As could be expected in the light of lockdown restrictions, electronic methods were mentioned frequently, with social media playing an important role.

> A range of materials appeared as Covid-19 took over our world … We posted these on our Facebook groups, and made them available on websites and through organisations such as (name of organization). [OT6]

> Setting up a Whats App group (for) sharing ideas. [SLT8]

Besides disseminating information themselves, participants also reported assisting youth to access credible and reliable information on the internet.

> I have a 14-year-old learner that uses (name of) software on a tablet to communicate. About 8 weeks ago he wanted more information regarding the symptoms of COVID -19. I gave him time after therapy to access the information and he immediately went to YouTube. I asked him why YouTube he said it's easier to watch a video because he can only read in pictures. We then had to have a discussion on using reputable sources of information, safe internet use … . [SLT10]

Other strategies mentioned included training communication partners, training other healthcare providers or educators, collaborating and teaming with other healthcare providers, and ensuring that information formats are tailored to the individual.

Health topics to be covered

A variety of Covid-19-related and general health topics were highlighted by the participants. Regarding Covid-19, topics related to disease prevention were frequently mentioned. These included social distancing, wearing of masks, hand-washing, as well as specific strategies for crowded home spaces, public transport, and educational settings. Managing health risks was a related topic, including the reasons for and applications of lockdown rules in various situations.

> … specific information regarding COVID 19 regulations need to be shared with our YA (young adults) in a manner that will assist them to understand why these regulations are in place and what are the implications of these regulations. [SLT2]

Understanding the disease was another important topic. This included disease physiology, symptoms, spread, and risk of co-morbidities.

> For some individuals, simple infographics on germs and how they spread may be useful. [SLT3]

Coping and mental health during the pandemic were also mentioned. Coping with loneliness, boredom, anxiety, domestic violence, as well as death and loss were highlighted.

Furthermore, participants indicated that information about disease management and diagnostic procedures should also be made available.

Apart from topics that were specifically related to Covid-19, participants also mentioned broader health-related topics – these are relevant during the pandemic but also beyond. Healthy living and health management were frequently mentioned. This included topics like nutrition, exercise, hygiene, sexual health and sexuality education, mental health, safety in and out of the house, addiction, family and relational health, and emotional well-being. Furthermore, participants also felt that youth with CCN needed more access to information about specific diagnoses and conditions, particularly their own diagnosis and possible co-morbidities.

> Young adults need to understand their diagnosis in its simplest form. [SLT14]

Understanding the health system, how to navigate it and having information about available services was another relevant topic. Lastly, topics related to patient rights and responsibilities, empowerment, and communication management in healthcare encounters were also mentioned.

> Youth with disabilities need to be made aware of the fact that not only are there policies and legislation that supports them but that regardless of the presence of an impairment, reasonable accommodations need to be made … . [SLT14]

Resources and strategies needed

Under this theme, comments were made about (1) the characteristics, formats, and presentation of health information, (2) resources and strategies for specific contexts, and (3) other resources and strategies.

Regarding the characteristics, formats, and presentation of health information, participants indicated that information should be authentic, reliable, culturally relevant, clear, and phrased in accessible language.

> (Videos should be) culturally relevant and relatable, ideally real-life actors or illustrated scenarios that mirror real life interactions and discussions about Covid and what to do/not to do. [SLT11]

Visual formats were mentioned frequently, with particular focus on graphics and pictures.

> … all topics covered should be accompanied by picture symbols that will provide youth with access to communicate about the topic. [SLT10]

Auditory formats, such as those provided by screen readers or text-to-speech technology, as well as audio files, were also mentioned. Furthermore, audio-visual formats and particularly videos were believed to be relevant, as participants described them as potentially engaging and memorable.

> I think access to video formats … would be a wonderful way to motivate youth to access more health information. Would it not be great if there was access to a YouTube channel created by the Department of Health that contains relevant videos and explanations with visual supports of common disorders or health issues that affect the youth of our country including information on COVID 19. [SLT2]

The importance of making resources available in multiple modalities was highlighted repeatedly. Although electronic formats were emphasised, some participants mentioned that hard copy formats (e.g., pamphlets) would still be needed for those without access to data and devices. Participants also stressed that resources should be made available in all 11 official South African languages, and also in sign language.

The participants discussed resources needed for specific contexts, mentioning health encounters and group or individual health education situations.

> Picture based counselling tools (e.g. talking mats) should be available in all clinics and wards to facilitate any session. [SLT12]

Methods in which public health information could be made more accessible were also mentioned.

> I think having posters available in public spaces (would) work really well. [SLT13]

> Educational content could be displayed on … TV with closed captions. [SLT12]

Other strategies mentioned included providing training and guidance to healthcare practitioners and other support persons, providing training to and supporting the empowerment of youth with CCN to be assertive about their rights to access to information, providing technology and data to access information, and obtaining policy and legislative support for communication access.

> I would strongly encourage a rights-based approach be employed whereby youth with disabilities take on more of an empowering role. [SLT14]

> I feel strongly that this form of inclusion (training healthcare professionals to use communication support material) needs to be included from a regulations point of view so that adherence to its use can be enforced – rather than left to the "goodwill" of individuals. Access to communication is a right – we have come so far with the rights to physical access (e.g. ramps, lifts, widened doorways) but communication access rights have not received the same kind of attention. Another example of the bias towards "visible disabilities." [SLT7]

Discussion

Youth with CCN in South Africa were reported to face various barriers in accessing health information during the pandemic. Health information (including public health information made available by the South African government) was typically not adapted or made accessible to them in a way that aligned to their abilities and/or resources (e.g., lack of access to the internet). The credibility of much of the information was perceived to be questionable, whereas more credible sources often presented information in complex and inaccessible written language. School-based health education programs in schools for learners with special educational needs seemed to be largely absent, in spite of the Integrated School Health Policy [14]. There was a perception that healthcare providers in general lacked the knowledge, skill, or willingness to adapt their communication style or use appropriate supportive resources in their interactions with youth. In addition, communication during healthcare encounters was often conducted while wearing masks, under time pressure, in noisy and stressful environments. These findings support those made in other contexts and confirm that a vulnerable group such as persons with disabilities have often not been specifically considered in the pandemic response [2–6].

This is the continuation of a phenomenon that predates the pandemic where the needs of persons with disabilities have generally been neglected in emergency responses such as in responses to natural disasters [32,33], in spite of the fact that they are typically more vulnerable in such situations. In extreme cases, disability status has been directly or indirectly considered in triage protocols, including those employed during the Covid-19 pandemic [7,34]. For example, based on frailty assessments scores, people with physical disabilities who are mildly or severely frail may not be prioritised for ICU admission or ventilator access in South African hospitals [8]. This suggests an ableist perspective and severe violation of the human rights of persons with disabilities [35]. A lack of accessible health information during the Covid-19 pandemic similarly violates the right to access to quality healthcare as enshrined in Article 25 of the CRPD [9], similarly reflecting ableism and bias against persons with CCN.

The participants in this study were all allied health professionals working directly with youth with CCN and their families. All participants had used creative strategies and materials to support access to health information and education for youth with CCN whom they supported. These strategies included supporting comprehension through concretised information presented with the help of visual aids such as schedules and communication boards. The support of comprehension is particularly important, in order that individuals with CCN (and also individuals who may speak a different language from the healthcare provider) can fully exercise their right to autonomous decision-making with regard to questions concerning their health and healthcare. Through the use of AAC strategies it is possible to provide comprehension support [17,36].

Expression was supported by strategies such as ensuring that relevant graphic symbol-based vocabulary was available to youth in preparation for health encounters in order for them to engage with healthcare providers and ask relevant questions. During health encounters and health education sessions, the use of objects, demonstrations, interactive games, and Talking Mats™ were reported to have facilitated engagement. Various similar strategies have been found helpful in a variety of healthcare settings [17].

Participants had furthermore disseminated accessible information through a variety of channels and also trained communication partners and other professionals in an effort to increase access to health information for youth with CCN. It was clear that participants had mostly relied on their own creativity and resources to make health information accessible to youth with CCN. No mention was made of initiatives or efforts from national government or from the provincial or national health department to make accessible information available. Although becoming resourceful is a positive response to resource-limited situations that has previously been noted amongst South African rehabilitation professionals [37], the reach of strategies and materials often remains limited to those individuals with whom the rehabilitation professional has direct contact. The lack of a concerted government-driven effort in South Africa to make credible, reliable, and accessible health information about the pandemic available nationally has also been noted by McKinney et al. [8].

Regarding health topics of importance to youth with CCN during the pandemic, many of these were related to understanding Covid-19 and its effective prevention and management. Participants emphasised that in order to increase compliance it is important that reasons for regulations are understood. This is affirmed by previous evidence on increased compliance with health protocols when alternative communication formats are used to provide information [38,39].

Apart from topics directly related to the disease and its management, topics addressing the collateral effects of the pandemic and lockdown restrictions on mental health and family well-being were also highlighted. The damaging effects of the Covid-19 pandemic on mental health have been noted by various authors [40–42]. Groups particularly at risk include those with pre-existing physical or mental health conditions, those more vulnerable to infection by the disease, and those with less means to access interventions. These factors may all be present to a higher degree in youth with CCN. Youth with disabilities are often reliant on regular educational and therapeutic interventions through the school system or other vocational or care facilities. Lockdown restrictions that resulted in school and facility closures left youths

in the full time care of their families, who often have few resources to meaningfully support them [8]. Boredom, social isolation, and loneliness affect not only the mental health of youth with CCN, but also that of the whole family. Adverse mental health effects are exacerbated by limited access to information and/or the spread of misinformation [42]. The increased risk for mental health effects underline the importance of addressing this topic with appropriate support strategies, including accessible information and education about looking after and maintaining one's mental health.

In their discussion of resources and strategies needed to improve access to health information and education for youth with CCN, the participants' desire to see larger and more sustainable efforts undergirded by policy and regulatory protocols was evident. They emphasised the need for public health information to be made available in a variety of modalities and languages aligned to the abilities and characteristics of youth with CCN. Videos were specifically highlighted as a possibly useful resource for information sharing and health education. A systematic review by Tuong et al. [43] confirmed that videos can be effective tools in modifying health behaviours. They can be cost effective compared to individualised face-to-face health education, and content can be controlled for quality and standardisation. They have been found appropriate for persons with low literacy and low health literacy [44] and have been successfully employed in low resource contexts [45]. Their format allows for dissemination via a number of channels, such as television, internet-based media channels, and social media. As such, they could be effective tools to spread reliable information in an accessible, multimodal, and multilingual format.

Participants also mentioned that their own efforts, in, for example, changing health protocols in direct health encounters to make communication exchanges more successful for youth with CCN, were hampered by a lack of regulations. High-level policies and legislation such as the South African Constitution [10] and the National Health Act [11] do not include clear implementation mandates on ground level and protocols need to be developed on a more local level to give effect to the rights enshrined in national legislation. Such mandates are therefore also needed to ensure that health protocols employed in all healthcare settings are inclusive and accessible to youth with CCN.

A rights-based approach was also evident in participants' emphasis that youth themselves should be encouraged to know and insist on their rights to access and receive quality healthcare as well as accessible and understandable health information. Disempowerment from a lifetime of being excluded from decision-making can manifest in passivity during healthcare encounters by persons with communication disorders [13]. Encouraging persons with disabilities to literally and figuratively "find their voice" can be an effective strategy to bring about policy implementation [46,47].

Providing training to youth, their support persons (e.g., family members), as well as to healthcare providers was repeatedly highlighted as a great need. Participants felt strongly that accessible health information and education resources needed to go hand-in-hand with training and creating opportunities to engage with youth about health topics and questions. As one participant put it:

> Providing accessible information – good
>
> Ensuring comprehension of the information – better
>
> Interacting with the information and others – best of all! [OT6]

This echoes previous sentiments that provision of AAC systems and communication support materials alone often does not adequately improve access to health information [19]. Training of all communication partners, and particularly healthcare providers, is an urgent necessity. Not only should healthcare providers be versed in using communication supports and adapting information to be accessible to persons with CCN, but they should also fundamentally respect the rights of all patients, including those with CCN or other communication-related risk factors, to access health information and to actively participate in the management of their healthcare.

Conclusions

The South African rehabilitation professionals participating in this study actively engaged in bridging some of the gaps in the Covid-19 pandemic response that excluded youth with CCN and others with communication-related risk factors from accessing reliable and credible health information. However, it is clear that more needs to be done in order to give effect to the right to equal access to healthcare for youth with CCN as enshrined in the CRPD [9], the South African Constitution [10], and the National Health Act [11]. Making simple, relevant, clear, reliable, and credible health information available in a variety of formats, in a variety of languages, and on a variety of Covid-19 and general health topics was identified as an urgent need. In response to these suggestions as well as those obtained from youth with CCN themselves and their family members, a range of resources were co-developed with youth with CCN [24] and made available for download from the authors' institutional website (https://www.up.ac.za/centre-for-augmentative-alternative-communication/article/2938080/co-designing-health-education-materials-). A number of workshops to introduce these resources to interested parties were also conducted. Further research is needed to evaluate the utility of these resources as well as their effectiveness in making health education and information accessible to youth with CCN.

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