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Street-connected children with communication disabilities and their caregivers in Western Kenya: experiences, beliefs and needs.

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Abstract

Purpose: Although street-connected children with communication disability have been identified in Western Kenya, little is currently known about the impact of communication disability on this group. In order to inform future service development, this qualitative study sought to understand the experiences, views and needs of street-connected children with communication disability, and of their caregivers at home and at school. *Materials and methods:* 13 children, 12 caregivers and 12 school-based Learning Support Assistants participated in interactive sessions, semi-structured interviews and focus groups respectively. Interviews were translated, transcribed and analysed thematically, using framework analysis. *Results:* Six main themes, with sub-themes, were identified: understanding and awareness of communication disability; the role of others; needs of the children and what might help; impact on those supporting the children; caregiver and Learning Support Assistant needs: support to better help the child; thoughts about the future. Participants' responses highlighted the importance of improving others' attitudes, awareness and willingness to adapt their communication, as well as a need for trusted relationships and some specialist help. *Conclusion:* organisations working with street-connected children should take communication disability into account in their services and interventions. Input based on a social model of disability is likely to be acceptable.

Keywords: communication disability; street-connections; children; caregiver; community; education; sub-Saharan Africa

Introduction

Children with street connections face a range of challenges, including the hostile perceptions of others, exposure to violence and lack of access to basic rights, such as health and education [1]. The term “street-connected” describes “children who depend on the streets for their survival – whether they live on the streets, work on the streets, have support networks on the streets, or a combination of the three” [2]. It is generally accepted that there are no reliable estimates of numbers of street-connected children globally. Reasons for children’s street connections are complex, resulting from a combination of ‘push’ factors, including poverty and unstable home environments, and ‘pull’ factors such as perceived freedom, financial independence and street-based relationships [1].

Kenya, located in Sub-Saharan Africa, has a population of 38.3 million, 19.15 million of whom are children. Despite advances in development, the country continues to experience widespread poverty, with 46% of the population living below the poverty line [3]. In 2007 there were an estimated 250,000- 300,000 children living and working on the streets across Kenya [4].

Non-governmental organisations working with street-connected children in Kisumu, Kenya’s third largest city, informally report that a disproportionate number of street-connected children screened have disabilities, including communication disability (2017 email from R. Gibson, YellowHouse Outreach Services to Author 4; unreferenced). Communication disability arises from impairments in communication, which can occur in isolation, for example a stammer or a language disorder, or alongside other conditions, such as autism and cerebral palsy. These impairments result in people having difficulties in understanding and/or expressing themselves in spoken and/or signed language [5]. Hartley's [6] biopsychosocial definition of communication disability recognises that the disability that a person experiences as a result of a communication impairment is a consequence of a combination of the direct effects of their impairment and the extent of societal adaptation to their needs. It is often considered a 'hidden' disability and, even within the wider community of disabled people, those with communication disability can be marginalised since their atypical communication can make it harder for them to participate and be heard [7]. It has been recognised that speech, language and communication are important to the achievement of the United Nations Sustainable Development Goals [8].

Communication disability is not yet well understood in sub-Saharan Africa, particularly at community level. Some studies have investigated the perceptions and experiences of caregivers and the community in relation to disability more generally e.g. [9,10] or to specific disabilities, such as visual impairment [11] or cerebral palsy [12]. These studies shed some light on how communication disability is viewed. Fewer studies, however, have focussed specifically on community disability. In Kenya, a wide range of perceptions reflecting some confusion about communication disability has been uncovered amongst members of community groups, including people with disabilities [13]. In Ghana, community members have reported how, in hypothetical situations, they would respond to and seek help for people with communication disability, again giving some insight into perceptions and beliefs [14]. Educationally, although inclusion of children with special needs, including communication disability, is national policy in Kenya, access and participation remains relatively low across the country [15]. Whilst many teachers are broadly positive about the concept of inclusion, understanding of disability remains limited, attitudes can be slow to change and many teachers report that they feel inadequately trained [16,17].

Organisations in Kisumu working with street-connected children have recognised that those children who also have communication disability may have need of additional intervention and services. The purpose of this study was to begin the process of defining appropriate, culturally relevant support for street-connected children with communication disability by seeking out the views of the children themselves and of those who care for them when at home and in school. The World Report on Disability [18] acknowledges that “people with disabilities often have unique insights into their disability and their situation” and recommends that they should be involved in policy and service formulation. Similarly, it has been recommended that policies, plans and interventions for street-connected children should be informed by the views of the children themselves [1]. Specifically, this study aimed to investigate the understanding, experiences and needs of street-connected children with communication disability in western Kenya, and those of their caregivers and support workers in school.

Methods

Research approach

The research was designed as a qualitative study, using thematic analysis with a phenomenological approach [19,p.16], to uncover how participants subjectively experience, understand and make sense of children’s communication disability, and to reveal their views about impact and support needs. A combination of individual semi-structured interviews, interactive activities and focus groups were used, as appropriate data collection methods for eliciting in-depth participant responses [19,p.29-34]

Study setting and participants

The research was conducted alongside, and complementary to, the 'LEAP from the Street: Learning, Education and Protecting' programme, a four-year (2016-2019) non-governmental organisation (NGO) programme in western Kenya [20]. The 'LEAP from the street: Learning, Education and Protecting' programme aimed to provide a comprehensive package of support and reintegration for street-connected children, including those with disabilities. For children deemed to have special educational needs, the programme included improving access to education through teacher training in inclusive education and the provision of community Learning Support Assistants in schools. 'LEAP from the street: Learning, Education and Protecting' programme Learning Support Assistants were recruited from the community, e.g. leaders and retired teachers, and trained to support 2-5 individual children in school, on a part time basis. They also had a role in advocating for the children's rights in the family and community [21]. This research study took place within the catchment area of the 'LEAP from the street: Learning, Education and Protecting' programme, i.e. the city of Kisumu and surrounding districts of Vihiga and Kakamega. The area covers urban, peri-urban and rural settings and is linguistically, culturally and economically diverse, with inhabitants mainly from the Luo and Luhuya communities.

All research participants were already involved with the 'LEAP from the street: Learning, Education and Protecting' programme. Three groups were included: street-connected children with already identified communication disabilities, aged 6-15 years; primary caregivers of street-connected children with communication disability and Learning Support Assistants who had been working with the children in school.

Sampling and recruitment

On entry to the 'LEAP from the street: Learning, Education and Protecting' programme all children were initially assessed for educational needs at their local government run Education Assessment and Resource Centre. If the centre staff had concerns about the child's communication they were referred on to local speech and language therapists working for the 'LEAP from the street: Learning, Education and Protecting' programme. Due to a lack of standardised assessment instruments for speech, language and communication in the languages of sub-saharan Africa, therapists used (with permission) a local adaptation of the Spoken Language Assessment Profile for Use in (Sub-Saharan) Africa - Revised Edition (SLAP-R) [22] assessment, alongside clinical judgement based on experience. The adaptation, which screens for receptive and expressive language and phonology/articulation, is available on request from the authors. The assessment was carried out in the child's mother tongue, using an interpreter where required, with the main purpose of assessment being to inform Individual Education Plans (IEPs). For recruitment to the research, 'LEAP from the street: Learning, Education and Protecting' programme records were consulted and children with communication disability clearly identified by this process were considered for inclusion. Based on the speech and language therapists' recorded diagnoses, the children's primary communication disability was categorised into one of 4 groups for the research: stammering; language disorder (receptive and/or expressive); social communication difficulties; communication disabilities associated with learning disabilities. These groups were kept broad to preserve anonymity of participants. A purposive sample of participants [23,p.56] with experience of a range of these communication disability categories and from a range of demographic and geographical backgrounds were recruited.

Primary caregivers of the selected children were initially approached by a familiar member of the 'LEAP from the street: Learning, Education and Protecting' programme team to invite them to participate in the research. If they showed interest, a trained member of the research team took informed consent for their child's participation and/or their own participation. It was not necessary for both child and caregiver to participate. Assent was also obtained for children over 8. All participant information sheets and consent forms were available in the main languages of the region, Dholuo and Kiswahili, and in English, in full, easy read and symbol form and were discussed verbally (with translation to other local languages if needed) with potential participants. Consent/assent was obtained for thirteen children, eight of whom were 10 years and under. The children had been supported by Learning Support Assistants in school for between 6 and 24 months. Twelve caregivers, including mothers, fathers, aunts and grandmothers from urban, peri-urban and rural settings consented.

Twelve Learning Support Assistants with experience of supporting children with communication disability were recruited through their local supervision groups and informed consent was obtained. Nine Learning Support Assistants were semi-retired, with previous occupations including teacher, social worker, counsellor and health worker; three were previously high school students or unemployed. This sample size was estimated to be large enough to obtain sufficient data and to include participants from a range of geographical, family and educational contexts, within the resources available [23,p.55]. Participant characteristics are summarised in tables 1 and 2.

[table 1 about here]

[table 2 about here]

Researchers, roles and reflexivity

The UK field team (Authors 1 and 4) are speech and language therapists (SLTs) with experience of research in low and middle income countries, including sub-Saharan Africa. A secondary aim of the study was to develop local research capacity [24]. The UK field team trained a group of eleven Kisumu-based 'LEAP from the street: Learning, Education and Protecting' programme staff, who were conversant with the local languages and cultures and had experience of working with the participant groups. This Kenya team included SLTs, counsellors, parent liaison officers and teachers. Training covered ethical research, informed consent, qualitative interviewing techniques, translation and transcription. Both the UK and the Kenya teams contributed to the design and trialling of participant information sheets, consent forms, topic guides and interactive activities for the children's sessions. The Kenya team conducted all informed consent, data collection, translation and transcription under the direction of a local lead (Author 3), also an SLT. The UK team led the analyses. Collaboration and reflective discussion at all stages of the research helped to surface and thus minimise bias that individual team members might bring through their own personal experiences and cultural backgrounds, and to consider what impact these may be having on the research [25].

Ethical approval for this study was obtained from Manchester Metropolitan University and from Maseno University Ethics Review Committee (MUERC). A research permit was also granted by Kenya's National Committee for Science and Technology and Innovation (NACOSTI/P/18/68964/20448).

Data Collection

Biographical data for participants were obtained from the 'LEAP from the street: Learning, Education and Protecting' programme records. Caregivers took part in individual semi-structured interviews at home, using their preferred language/s. Learning Support Assistants were invited to one of two focus groups, conducted in English as the common language used in the workplace. Children took part in individual interactive sessions at home or school, in their preferred language. Since the children had varying levels of mild to moderate communication disability, a range of activities were developed to make the session as interactive and accessible as possible. These included warm-up activities to establish rapport; the use of photos of everyday scenarios to elicit opinions (from simple yes/no and like/don't like closed responses, to more detailed descriptions if the child was able); a 'circle of friends' activity to discuss relationships; and a drawing activity to elicit discussion about the future. Topic guides for each participant group are given in the supplementary material (supplementary tables S2, S3, S4).

All sessions were audio-recorded and lasted 30-60 minutes. Each caregiver and each child session was translated into English and transcribed in a single stage by the Kenya team, with a focus on translating fully and for meaning. This was particularly relevant for the children's interviews, where no attempt was made to reproduce the child's communication errors in English on the transcripts, instead the closest translation of their meaning was transcribed at a roughly equivalent language level (single words, short phrases etc). Learning Support Assistant focus groups were transcribed verbatim by the Kenyan team and checked by Author 1.

Data analysis was led by the UK team, with the Kenya team contributing prior to finalising themes. The analysis was thematic, drawing on the stages of the Framework method as described by Gale et al. [26].   The Framework method allows for a combination of deductive coding based on the research questions and inductive coding of ideas generated from the transcripts. NVivo 11 Pro was used to organise the data and facilitate coding. Data from each participant group was initially analysed separately. The stages of analysis are described in table 3.

[Table 3 about here]

Before finalising, key themes and messages for each participant group were presented at Learning Support Assistant and caregiver respondent validation meetings and at a separate meeting for the Kenya research team. Presenting analysed data from the group sample is considered appropriate where the purpose of the validation is to seek views on plausibility and resonance with participants experience [27]. These views were considered alongside the original analysis memos to finalise themes for each group. Themes were then compared for commonalities and discrepancies across groups to develop the overall themes presented here.

Results

Six main themes developed from the data of the 3 participant groups, are reported here (table 4). For each theme a brief overview is given, then caregiver, Learning Support Assistant and child contributions to the theme and sub-themes are presented.

[Table 4 about here]

1 Understanding and awareness of communication disability

Caregivers and Learning Support Assistants discussed their understanding and awareness of communication disability, and their beliefs about possible causes, at some length. Children were only asked directly about communication disability if they showed some awareness and willingness to discuss their difficulties; only a few gave insight into how they understand their communication disability.

1.1 Awareness and understanding develop with time and experience

Most caregivers showed some understanding of communication disability and, although not using diagnostic labels, were aware of and able to describe the specific difficulties their child had with communication and/or social interaction. This was learned over time: *'I understand her after having stayed and observing her for a long period' [CG06].* Many had not initially recognised the child's difficulties. Some had originally attributed these to the child being 'difficult', even punishing the child: *'I have happened to beat him once since he was born but I have come to understand him that he has that problem' [CG05].* Only one caregiver did not recognise communication disability in his/her child: '*He communicates very well, no problem' [CG11].*

Like caregivers, Learning Support Assistants also tended to talk about communication disability without reference to specific diagnostic labels, instead simply describing the sorts of difficulties with communication they had observed in children they worked with. Learning Support Assistants showed a broader understanding of communication disability, more often mentioning the two-way nature of communication and the possibility of difficulties in either expression or understanding, reflecting the range of their experience: *'one is not able to effectively express ... {one] may not be able to encode the message communicated to him or her by another person [LSA10].*

The children's responses showed differing levels of awareness of their difficulties. Many did not talk either directly or indirectly about their communication. Some showed lack of awareness: *Interviewer: 'How do you feel about your speaking?' Child: 'good, I have no problem with it' Interviewer: 'What of your understanding? Child: 'the same' [CH10].* Others were aware that they had difficulties, for example in being understood, but did not know why: *Interviewer: 'Why do you think they don't understand you? Child: because they don't want to understand me' [CH03].* Those with stammers showed most awareness and some also talked about emotions around their speaking: *'I feel bad...because I can't talk well and I have a lot of stops and blocks in my speech' [CH05].*

1.2 Causal beliefs are influenced by own experiences and child's history.

As a group, caregivers gave a wide range of beliefs about what might have caused communication disability. For some, incidents in the child's life, such as accidents or sickness, were blamed, especially when the child was believed to have been developing typically before: *'when he was 2 years old he felt sick with serious infection... before that he was speaking fluently without hitches but after that he started experiencing communication difficulties' [CG04].* Others were influenced by their own experiences; one who had worked in a hospital had seen many examples of children with communication disability and held medical causal beliefs, another knew of others in the family with communication disability and believed it to be inherited: *'This problem I think is just from the family. It is in the family of the child where the mother was born' [CG10].* Some acknowledged the beliefs of their neighbours or others in the community but dismissed these ideas: '*people say is that when a* *baby is feeding on eggs then it might cause communication disability, but I don't believe in that [CG03].* A number reported that while they knew others might blame a curse or witchcraft, they themselves did not believe this: *'I cannot say that it's witchcraft or something else like other parents say' [CG09]; 'I may not be well conversant with what causes communication disability but what I know is that it is something natural' [CG01].*

The Learning Support Assistants were working with the children as a result of their history of street connections and whilst they proposed a range of medical causes (including genetics, illness, accident and epilepsy), environmental causes such as neglect, trauma, cruelty and abuse also figured highly in their responses: '*if a child is given birth to and then abandoned, the harassment the child will get outside may put that child to never talk or talk things that cannot be understood' [LSA08].* A couple also proposed language barriers as a cause i.e. the language of school not being the mother tongue or the 'street slang'(sheng) the children were used to: *'Maybe the child he was used to his mother tongue, so when he goes to school and finds a foreign language, adapting to the language might be an issue' [LSA04].*

Only one child gave a response that indicated a causal belief, and this was medically oriented *'the doctor can look into my mouth and remove those things that are making not speak well' [CH13].*

2 The role of others

2.1 Others influence the experience of communication disability

Participants from all three groups gave examples of the attitudes and behaviours of other children and adults towards the children with communication disability. Many saw these as influencing the impact of the communication disability on the children. While caregivers discussed mainly the impact of others on the child's emotions, relationships and participation at home, Learning Support Assistants also focussed on the impact on learning.

A number of caregivers described supportive relationships with other children, talking about their child's friends and the games they enjoy: *'My child has no difficulty in associating with other child, he plays with them and they respect him the way he is' [CG03].* More negative experiences were also reported, with teasing, mocking and hitting being common themes, even when the child was described as having many friends. Caregivers often felt the actions of peers towards the child's communication disability influenced their child's own behaviour and social participation. Withdrawal from social situations, *'sometimes they harass him. That's why he decides not to play with them' [CG08]* or reactive responses *'He doesn't like playing with other children because they keep on insulting him and that can make him fight' [CG04]* were common. While some caregivers chose to encourage their child to keep away from other children to avoid trouble, one took a different view: *'I always leave my child to play with other children. I know other children, but I cannot deny my child the right to play with other children. I know when they play, he learns from other children' [CG07]*

Caregivers felt that many adults in the community either do not understand communication disability, *'My neighbours are not sure about this… I think they do not have any idea about it' [CG02]* or have negative misconceptions: *'other people take him to be rude' [CG05].* Conversely, some community members were described as being more supportive, lessening the impact of the communication disability on the child's participation: *'buying few items for our daily use… he enjoys doing that. He does it with no difficulties because shopkeeper understands him' [CG07].*

Learning Support Assistants also discussed the attitudes and behaviours of others towards the child with communication disability, focussing on the impact that these might have on their well-being, learning and participation in school: *'If the teachers…have a positive attitude towards these children and support them, then they'll have a positive attitude* *towards learning. But if the teachers have a negative attitude towards these children and probably give them names, then the children will have a negative attitude towards learning' [LSA10].* Learning Support Assistants described having observed a range of attitudes in people around the child. Negative attitudes and behaviours, such as laughing at the child, ignoring them and not giving them enough time to communicate, were linked with tendencies of the child to withdraw, have low self-esteem and fear talking in class: *'those children then laughed at him, the other children, they laughed at him. So this will demoralize everything and the performance also, so this child cannot participate' [LSA06]*; *'a child who is stammering, so it gets him, at times he gets withdrawn because…the peers, they get, like they don't want to get to listen to what he is saying, because he's always late with talking' [LSA03].* Conversely, Learning Support Assistants felt that when the children experienced positive attitudes and encouragement from others, this encouraged participation: *'If they stammer and then you always encourage them just to talk, then your class is also accepting them, they'll communicate very well and they'll participate' [LSA08].*

All the children talked about and named at least one friend and most described their friends as children who accept and play with them or help them, either in schoolwork or with chores: *'D is my best friend… He helps me at school when I face difficulties in class such as reading and answering questions' [CH03].* A number talked about how friends could understand them and how they enjoyed chatting with their friends: *Interviewer: 'Do you have many friends?' Child: 'yes' Interviewer: 'Do speak with them?' Child: 'yes' Interviewer: 'How do you feel when you are speaking with them?' Child: 'good' [CH02].* Some children saw their peers as sources of support and described looking to them for help in class: *'when I don't understand what the teacher is teaching, I go to my friend and ask her to help me and she helps me' [CH10].* However, nearly all had also had negative experiences with other children, *'there are some children who abuse me at times they laugh at me' [CH05]* and some simply found relationships difficult: *'Playing with the other children is what is difficult' [CH08].*

The children mostly reported that school staff were supportive: *'My teachers are good to me' [CH05]*, but one feared he would be punished for his communication disability and another had experienced anger from his teacher when he was unable to do the work: *'The teacher gives us a lot of work and when I'm unable to do, he gets angry' [CH11].*

2.2 Experience and familiarity can change attitudes

Caregivers who had experienced some positive attitudes from the community felt that efforts to raise the community's understanding and awareness of communication disability would be useful: *'that can help them...so that they can know that these children are just like other children' [CG10]*. Those who had reported negative attitudes of others were less optimistic: '*Even if you call people, some may come but not all. Maybe 3 to 5 people will show up and they'll see it something not useful and wish to go back to their work' [CG12].* Some caregivers suggested that attitudes would more likely be changed through contact with children with communication disability and positive role models, with a ripple effect from parents and trained workers to the community: *'Maybe if you can do something that people can see with their eyes' [CG10]; 'the way you've come here, the child is being supported by many people not only teachers. Even other people have come and have seen the improvements in the child. From there people start understanding' [CG09].* Similarly, one caregiver suggested that through playing with her child with communication disability other children became more accepting: *'I used to encourage him to play with other children and later they started accommodating him' [CG07].*

Learning Support Assistants saw increasing awareness of communication disability and encouraging acceptance of and positive attitudes to the children as important for their welfare and learning. They acknowledged the challenges faced by teachers with large classes and expressed that this might contribute to limited awareness and negative attitudes: *'May be {teacher} does not identify the challenges the child is undergoing and sometimes when a child failed, he can or she can develop a negative attitude towards this child by not know that this child having a problem' [LSA12].* Some Learning Support Assistants talked about how the experience of working with a child with communication disability had changed their own attitudes: *'before I used to take them as children who cannot be integrated into class, you cannot teach them anything, but since I have started working with them my perception of them has really changed' [LSA04]* and also of a ripple effect, whereby their own positive attitudes towards the children influenced other teachers and children in school: *'since I started working with the child with the communication disabilities, even the class teacher of that child has changed the attitudes towards that child' [LSA02].*

Only a few children gave opinions on raising awareness. Of these, most felt it would be good to tell adults and other children about communication disability as people could then help them, but one feared it would lead to punishment.

3. Needs of the children and what might help

In describing their perceptions of the children's needs and what might help, both Learning Support Assistants and caregivers focused mainly on improving the emotional well-being of the child, and on adaptations that would accommodate their communication disability and help them reach their potential. Both groups conveyed the message that if people could come together to support children with communication disability, then they could make a difference. Both also talked about a need for external, expert support as well as specialised resources. Most children were either unaware or found it difficult to spontaneously articulate their needs. Some talked about general help with their education and some were able to respond to guiding questions, giving some insight to their needs.

3.1 Emotional needs; improving self-esteem and well-being

Caregivers highlighted the emotional needs of their child; to be accepted, loved, supported, encouraged and listened to: *'Support and love is very important to children with communication disability' [CG03].* A number of caregivers suggested means to improving their child's emotional well-being, including education: *'Ooh if they can be supported in education…this can make them happy and this can raise their esteem' [CG02]* and encouraging self-acceptance: *'there are those who can train and counsel them…and this can enable them to cope with current situation, accept the way they are' [CG01].*

Similarly, many of the Learning Support Assistants placed improving the child's self-esteem, well-being and sense of belonging high in their descriptions of child needs and felt they could help by fostering trusted relationships: *'These children need a lot of patience and understanding them. You must know them well…They have to know you and you have to know them' [LSA08].* Acceptance by others and self-acceptance were considered important: '*We need to accept and encourage them to also accept themselves the way they are…. We need to encourage fellow children also to accept the children with communication disability the way they are' [LSA10].* Many Learning Support Assistants saw recognising and celebrating strengths as a possible route to increasing self-esteem: '*so you try to nurture that talent from the start so that it gets them motivated and self-esteem [LSA03].*

Children expressed some emotional and social needs indirectly through their descriptions of their 'perfect school'. Most described clean, safe, well-resourced physical environments, which provided necessities of food and water. One felt there needed to be less fighting amongst children in school, another noted school should have good friends and a number said the teachers should be good to them: '*good food, good uniform and good teachers...they have to be good and teach me well' [CH10].*

3.2 Effort from others; adapted communication and teaching methods

Caregivers described adaptations they had made in their own interactions with the child: *'If you tell him something, you must slower the speed.....slowly, slowly' [CG05]* and felt that others also needed to make an effort to understand and accommodate their child's needs: *'when he speaks, he gets stuck and if you are not keen, you will not get what he is saying' [CG07].* Caregivers also suggested teachers need to be more aware of the child's communication disability and adapt the pace of their teaching: *'if they can get someone who can explain to them slowly because when I look at my boy, he's not someone who needs a tough teacher [...] If you take him slowly, he understand' [CG12].*

Learning Support Assistants similarly talked about the need to accommodate the children by adapting their own communication, *'we need to give time for the children to contribute in class, not if the stammerer a word is not coming out then we finish it up for them' [LSA10]* and teaching methods: '*some subjects might be taught by using tangible things' [LSA01]*. Many assessed the individual support they were able to give the child as beneficial: *'if we give them that close attention they will get it right and their performance will come out very well' [LSA06]*. Some went further to suggest that the curriculum should be adapted to meet needs of different kinds of learners, including children with communication disability: *'when it comes to the syllabus, I know it's kind of complicated but we should have like a syllabus which includes all aspects of learning' [LSA03].*

With prompting, some children felt others should adapt their communication and teaching for their needs: *Interviewer: 'Would you want them to teach you slowly or at a fast pace?' Child: 'Slowly' Interviewer: 'What of the way they speak to you?' Child: I also want them to speak slowly' [CH11].* The children's responses revealed varied reactions to the teaching methods used in class. Despite their communication disability, some children reported enjoying having the same opportunities as other children to speak in class and participate, and liking individual, group and whole class teaching. For others, teaching methods that put the spotlight on the child (such as answering questions or reading in front of the class) induced fear which inhibited participation and learning.

3.3 Specialist intervention and resources

Some caregivers identified the possible role of experts and felt that specialist intervention or special schools might help: *'They need special schools, they also need to undergo counselling sessions' [CG06]; 'If we can get specialist who can assist them' [CG01].* Others expressed that there was no treatment or cure and that it is up to them and others to support the children: *'I know that it has no treatment and all we can do is support them' [CG06].*

Learning Support Assistants also felt that some of the children needed access to specialist intervention or resources: '*the ones with stammering need therapist cos I believe that when it's still in the early stages their speech can be corrected' [LSA03];* '*These children should be their side helped with some communication devices which can help them to communicate very well' [LSA12].*

One child also mentioned specialist intervention: *'They should take me to the doctor…so that the doctor can look into my mouth and remove those things that are making not speak well' [CH13].*

4. Impact on those supporting the children

Caregivers and Learning Support Assistants discussed the impact of supporting a child with communication disability on themselves. As might be expected, none of the children gave responses that suggested they had considered how their communication disability might impact on others and this theme was not present in the child interviews.

4.1 Additional responsibilities and burden

Many caregivers highlighted that the child's communication disability had little practical impact on them at home as the children were still able to carry out their chores: *'It's not a problem to me because he performs all his responsibilities as usual' [CG02].* Some however talked about the need to give them extra help: *'When I send him, I need to explain to him the things that I want' [CG12]* and the fact that everything takes more time: *'he's very slow. So something like that I really feel it now. So when I want do my things in a quicker way, he drags me behind' [CG05].* Impact was also discussed in terms of a change in role for caregiver and child: *'I really feel pity on myself because I wished that the child was going to help me' [CG12].* Most caregivers saw the child as their responsibility: '*this is my child and I understand him better. So he is my burden' [CG07].* They found themselves having to advocate for the child: *'I have to go to the teacher and tell her that the child is not doing good in such an area' [CG09]* and help them negotiate relationships: *'I told the other children to understand, give time and respect him, I also explained to them that he has communication disability' [CG04].*

4.2 Emotional impact

A few caregivers also mentioned the emotional impact of their child's communication disability on themselves: *'I'm not happy about it. Because that child used to understand properly but it reached a time when he couldn't understand well. How would you feel! You can't feel okay' [CG01].* For others, it was the behaviours of others towards the child that resulted in caregiver negative emotions: *'I find it hard for me when a visitor comes and tries to talk to him. He will stammer and the visitor will stop talking to him for they do not understand him and this makes me feel bad' [CG12]; 'jokes are there…but it hurts him and me too' [CG01].*

Learning Support Assistants, conversely, reported mainly positive impacts from working with the children; they had learnt patience, felt better able to relate to other children with and without disability, including within their own families: '*Working with these children through patience, it has made me, I can work anywhere with anybody and with any child' [LSA09].*

5. Caregiver and Learning Support Assistant ***needs; support to better help the child***

Caregiver and Learning Support Assistant responses showed that both groups wanted to be empowered to better help the children.

5.1 Training

Caregivers reported a need for more training so that they could better understand communication disability and learn how to help the child more themselves: *'Trainings on how to communicate with him and staying with him or taking care' [CG05].* Learning Support Assistants also wanted more training, *'we need to be empowered in terms of training on how to help these children with communication disability' [LSA10],* but also more support from others, *'we need the consent of the parent to support the children' [LSA03]* and more time with child in school *'to help them better I need to give them more time, more LSA [Learning Support Assistant] time in school' [LSA04].*

5.2 Financial support to provide a future

Caregivers also identified a need for financial support for themselves so that they in turn could support the child through education or vocational training to give the child better future opportunities and self-improvement: *'If you have money, a child can be trained to work. He can also have a choice' [CG09].*

5.3 Emotional and spiritual support

Despite some caregivers mentioning the impact, only one suggested that they might benefit from support for themselves to cope with the emotional demands of caring for a child with communication disability: *'such parents should be followed up to their households and be interviewed the same way you are now interviewing me. This can make them happy' [CG02].* There was, however, a more indirect, implicit idea that knowing that there is someone to help the child in school might reduce the burden and worry on themselves: *'if I get ... someone to teach her well at school it would help [me]' [CG06].* One Learning Support Assistant and one parent mentioned spiritual support: *'at least sometimes we go and talk to God to give you like knowledge and any other thing you need... at times we need the divine intervention' [LSA03].*

6. Thoughts about the future

The three participant groups all gave views on what the future might be like for the children, with most expressing a positive outlook, provided the children were supported to reach their potential, but some expressing some concerns.

5.1. An uncertain future; coping without support

Some caregivers worried that their child might find it hard to live independently without their support and cope with the pace of modern life: *His future life as I'm seeing according to the way people are doing thing faster, I always feel that he will be affected if he'll not be able to catch up with things [CG05].* One, in particular, expressed concern that without caregiver presence the child might be maltreated in future: *'I do not want her getting married [...] that person may hit her, mistreat her. I think it's better if I just stay with her' [CG06].* One

Learning Support Assistant expressed doubt over whether the children could have a good future if support had not been provided from a young enough age: '*I think when these children can be taken care of, they will have some great future but for children who some of them are 10 year, 11 year, 14 year but they have never talked for their life I don't know' [LSA07].*

5.2 A bright future; happiness, work and family

Caregivers hoped for their child to be happy and feel valued in the future. They talked about both family life and the work they might do. The majority hoped and expected that their child would marry and have children. Many of the caregivers valued education and saw support with this as the means to a good future: *'If he gets education, or if he performs well in his studies, am sure that he has a talent of getting a job' [CG02].* While some had high aspirations for their children to be, for example, a *'doctor' [CG03]* or an '*architect' [CG04]*, others felt the child would be better training to do manual work or helping in the homestead: *'When he grows up, first he has to go for a job like manual work, he can do' [CG11].* Some of the caregivers felt that personal characteristics their child had developed, such as a willingness to help people, work hard and show resilience, would help them towards a good future: *'As a result of difficult experiences that he has undergone I feel that his future will be bright' [CG04]*

Learning Support Assistants similarly expressed mainly positive visions of the future: *'even if you are maybe having a communication disability that does not hinder you from being somebody in the future' [LSA03].* Some saw child strengths and interests as a possible route to future work. Though these strengths were often non-academic, *'He might think about the outdoor activities rather than the indoors, that's what, then from the talent he might have a future' [LSA01],* a few Learning Support Assistants believed at least some of the children could achieve their more academic aspirations: *'That one wants to be a teacher and will be a good teacher from what I see' [LSA08].*

All but two of the children were able to express, through drawing and discussion, what work they wanted to do in the future. Many of these ambitions were aspirational, *'doctor' [CH03], 'pilot' [CH13], 'teacher' [CH07]*, a couple more practically based *'driver' [CH09], 'mechanic' [CH04]* or related to hobbies and interests, *'skater' [CH05]*. Some of the children said they were motivated to help people, *Interviewer:' Why do you want to become a nurse'? Child: 'so that I can help the sick' [CH10],* others to make lots of money, *Interviewer: 'What would you like to be when you grow up?' Child: 'someone who works in a bank'. Interviewer: 'Why would you want to work in a bank?' Child: 'I'll get a lot of money' [CH11]*. The majority of the children saw a future in which they were working, married and with children of their own.

Discussion

This research was conducted in a context where it has been recognised that some street-connected children are also living with communication disability. Little, however, was known about the children's understanding of communication disability, their experiences and perceived needs, and those of their caregivers and education providers.

Participants' responses shed light on how they view communication disability and, although the analysis was not based on the prevalent disability models, their accounts can be usefully discussed in relation to these. Disability models have broadly progressed from a medical model to social and human rights models [28]. In some cultures and circles a 'moral/religious' model [29] also pervades, whereby disability is viewed as a consequence of transgression on the part of the individual or family, or alternatively as a blessing from a higher entity, providing the opportunity to develop positive character traits such as patience and perseverance.

In contrast with many studies on disability from across sub-Sahara Africa that have reported community views consistent with the moral model (see [9] for examples), in this study, the moral view was not very prevalent in participant accounts of causal beliefs. While caregivers did report that others in the community might say the child's communication disability was the result of, for example, a curse, they themselves mostly either directly contradicted this view or only stated beliefs more consistent with medical or environmental causation. A similar disconnect between what caregivers believed and what they felt the community believed was reported for caregivers of children with cerebral palsy in Botswana [30]. All the caregivers in this study had had at least some contact with formal services and Learning Support Assistants had undergone training in disability and special needs, which may have influenced their thinking about causes. Other researchers have suggested that people may in fact hold a plurality of views, including both biomedical and moral model accounts, that allows them to make sense of disability within their context [9,31]. The lack of evidence for this in this case, may be because caregivers were less forthcoming about moral model views in the unfamiliar interview setting or it may be that, with direct experience and contact with formal services, views more aligned with medical or environmental explanations can gain traction.

The theme 'experience and familiarity can change attitudes' suggests that participants would support moves towards more inclusive environments for children with communication disability, in both education and the community. The importance of direct experience in promoting more positive attitudes has been recognised in research in sub-Saharan Africa on community disability education programmes [32] and on teacher training [16,33]. A meta-analysis of studies of interventions designed to promote positive changes in attitudes towards disability in children found that those involving direct and indirect contact with children with disability were most effective [34]. The idea that Learning Support Assistants saw themselves as role models in improving attitudes, both for school staff and other children, is of interest. This resonates with previous research in Kenyan schools suggesting that a community of committed educators could, through their own example, promote positive attitudes and inclusion [17]. Similarly, the finding that caregivers also feel that community attitudes might be best changed through example and 'seeing with their own eyes' validates the idea of the Learning Support Assistant role being extended beyond individual in-class support, to include awareness-raising and promoting attitudinal change, in both school and the community. Learning Support Assistants in the respondent validation group suggested they might do more in this capacity, including being an outreach worker from school to the wider community. Such a move would respond to the idea, espoused in both caregiver and Learning Support Assistant accounts, that the community and school should work together to support the children.

In relation to what participants thought would most help the children, views aligned with a social model of disability were evident. All participant groups reported that others, including other children, can be a source of difficulties or of support, and the sub-themes around impact and needs reflected this. Recognition of the need for effort from others to help the children and calls for more training, support and community awareness showed that caregivers and Learning Support Assistants saw a role for themselves and others in reducing the impact of communication disability on the children's lives. Given the accounts of the impact, both positive and negative, of other children's attitudes and behaviours, interventions aimed at raising the awareness of peers and helping them to interact with children with communication disability, may be particularly effective in this context, e.g. [35]. Running alongside these views was a more medically oriented perceived need for specialist input to ‘cure’ the impairment underlying the child’s communication disability. Research on likely help-seeking behaviours for people with communication disability in Ghana [14] reported a similar dual approach, of seeking both to ameliorate the impairment through remedies and teaching, as well as to improve the communication environment around the child. This suggests that impairment focussed interventions are also likely to be acceptable. Given the paucity of speech and language therapists in sub-Saharan Africa [36] caregiver or educator mediated interventions, where the adults around the child are taught intervention strategies, are likely to be most feasible and effective.

Children in this sample can be considered doubly vulnerable through the combination of their history of street connections and their communication disability, and all participant groups highlighted the emotional needs of this group of children. Street-connected children have articulated a desire for trusted non-judgemental relationships with people who will identify with them, be patient and listen to them [1]. This is supported by the findings of this study, exemplified by the prevalent idea in the children’s accounts that people should be ‘good to me’. Failure to address mental health and psycho-social well-being has been cited as a factor for street-connected children not completing rehabilitation programmes [37]. Effective communication underpins the development of the trusted relationships through which psychosocial wellbeing and mental health can be addressed. Those living and working with street-connected children with additional communication disability will need to learn how to adapt their own communication and interventions to the child’s communication level, to allow emotional needs to be met.

This small, initial study focusing on street-connected children with communication disabilities and their caregivers at home and school, is a first step towards listening to the views of these three important participant groups. Some limitations are acknowledged. Challenges in translation from a range of local languages into English may have reduced nuanced interpretation of the data. The use of some closed questions within some of the child interviews, although necessary to facilitate understanding, may have limited the richness of the data. Additionally, the full range of types and severity of communication disability seen in children was not represented.

The research has implications for organisations wishing to ensure their services for street-connected children are fully inclusive of those with communication disability, and for those interested in addressing communication disability in under-resourced settings, more generally. Interventions aimed at increasing community awareness, promoting positive attitudes amongst adults and other children, improving the communication environment around the child and increasing opportunities for participation at school and in the community, are likely to be acceptable to caregivers, education support workers and the children themselves. Intervention at this level does not require a large team of communication disability specialists, such as speech and language therapists, but does require a transfer of knowledge and expertise to committed individuals at community level, be these community rehabilitation workers, Learning Support Assistants, caregiver advocates or others. This is a potential role extension that the fledgling speech and language therapy profession in sub-Saharan Africa has already been challenged to embrace [7] and this research support efforts to develop and evaluate programmes to address communication disability in this way.

Despite their apparently sometimes difficult experiences and currently limited support, many of the children in this study and their caregivers have high hopes for their futures. The challenge for those working with such children is to ensure that they provide services and interventions that take account of the impact of the child’s communication disability, as well as their street connectedness and give them the opportunity to reach their potential.

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Declaration of interest

The authors declare no conflicts of interest

Data availability statement

The data that support the findings of this study are not available due to their containing information that could compromise the privacy of research participants.

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Table 1: Participant demographic information

Children (N=13)		N
Age	8-10 years	8
	11-15 years	5
Gender	Male	12
	Female	1
Home environment	Community	9
	Children's Home/ Institution	4
Length of time with Learning Support Assistant	<6 months	9
	7-18 months	4
Primary Caregivers (N=12)		
Relationship to child with communication disability	Mother	7
	Father	3
	Aunt	1
	Grandmother	1
Setting	Urban	6
	Peri-urban	1
	Rural	5
Learning Support Assistants (N=12)		
Gender	Male	6
	Female	6
Age (years)	20-39	6
	40-59	4
	>60	2
Previous occupation	Teacher	5
	Social Worker	2
	Counsellor	1
	Health care worker	1
	High school student	1
	None given	2
Length of time as Learning Support Assistant	<12 months	3
	12-24 months	9
No. children with communication disability supported	1	7
	2	4
	3	1

Table 2: Communication Disabilities represented in sample and quotes.

Primary communication disability	Children with communication disability	Caregivers of children with communication disability	Learning Support Assistant experience of supporting*
Stammering	CH02; CH05	CG02; CG03; CG05; CG10	LSA01; LSA02; LSA03; LSA04; LSA05; LSA09; LSA11
Language disorder (receptive and/or expressive)	CH03; CH06; CH07; CH11; CH12; CH13	CG01; CG04; CG06; CG09; CH10; CG12	LSA04; LSA06; LSA10; LSA12
Social communication/ pragmatics	CH01; CH04		LSA03; LSA06; LSA07; LSA08
Communication disability associated with Learning Disabilities	CH08; CH09; CH10	CG07; CG 08; CG11	LSA08

N.B. Groups are independent i.e. not all caregivers and Learning Support Assistants are associated with children in sample.

** Learning Support Assistants may support/have experience of a number of children with more than one type of primary communication disability.*

Table 3. Application of the stages of framework analysis.

Familiarisation	Transcripts read through; queries about translation or interpretation referred back to the interviewers for clarification.
Creating the analytical framework (AF)	First 3 caregiver and child interview transcripts and first Learning Support Assistant focus group transcript coded independently by authors 1 and 2. Working AF agreed for each participant group.
Indexing	Remaining transcripts coded according to the AFs; new or amended codes agreed after every 2 or 3 transcripts. All coding re-checked against the final scheme
Charting	For each participant group matrices drawn up in NVIVO based on the research questions and ideas generated by initial coding. Codes addressing similar concepts grouped together; participant's coded responses summarised in cells to facilitate within and across case observations
Mapping and interpretation	Authors 1 and 2 independently reviewed each matrix. Themes arising from both across and within case responses written up in analytical memos. Met to discuss and agree themes. Themes shared with author 4 for internal review.

Table 4. Summary of themes and subthemes

1. Understanding and awareness of communication disability 1.1 Awareness and understanding develop with time and experience 1.2 Causal beliefs are influenced by own experience and child's history
2. The role of others 2.1 Others influence the experience of communication disability 2.2 Experience and familiarity can change attitudes
3. Needs of the children and what might help 3.1 Emotional needs; improving self-esteem and well-being 3.2 Effort from others; adapted communication and teaching methods 3.3 Specialist intervention and resources
4. Impact on those supporting the children 4.1 Additional responsibilities and burden 4.2 Emotional impact
5. Caregiver and Learning Support Assistant needs; support to better help the child 5.1 Training 5.2 Financial support 5.3 Emotional and spiritual support
6. Thoughts about the future 6.1 An uncertain future; coping without support 6.2 A bright future; happiness, work and family