THE EARLY EDUCATION AND SUPPORT OF YOUNG DEAF CHILDREN AND THEIR CAREGIVERS IN GHANA

Working paper 2: Interviews with caregivers

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1 Introduction

This working paper reports on the second phase of a UK-Ghana collaborative project that examines the early education and support for young deaf children and their caregivers in Ghana. The project is funded by the British Academy’s Early Childhood Education (ECE) Programme, supported through the Global Challenges Research Fund. The principle aims of the project are to examine opportunities for quality ECE to help young deaf children in Ghana progress through early childhood developmentally ‘on track’ in terms of language, communication, learning, and psychosocial well-being.

1.1 Childhood deafness in the global south

Unidentified hearing loss is the most significant disability worldwide to have an impact on early development, with more than two-thirds of the population with a hearing loss living in the Global South (WHO 2020). 90% of babies born annually are born in low-middle income countries (LMICs). Less than 3% of these babies will receive hearing technologies and less than 10% will have access to early intervention and support (Störbeck, 2012).

The prevalence of childhood deafness and its associated factors is particularly high in Sub-Saharan Africa (SSA) where routine screening for hearing impairment and early intervention is not widely available. A child living in SSA is twice as likely to be deaf as a child in the developed world. In this, and other low-income contexts, childhood deafness is mainly associated with preventable and treatable causes such as prenatal and postnatal infections, birth-related causes, and ototoxic medicines. The high prevalence of infections resulting from poverty, malnutrition, and poor living conditions are also a predisposition for hearing impairment (Desalew et al., 2020).

Childhood deafness jeopardizes the rights of children to live full and individual lives and impacts on those responsible for their growth and well-being (Olusanya & Newton, 2007). Most crucially, deafness in the critical stages of early development compromises the acquisition of a language (sign or spoken) that is shared by family, community, and peers (Moeller et al., 2013). Unattended deafness at this early stage is ‘lost time’ for early language and communication development that subsequently compromises social and cognitive growth and impacts on
societal participation (Marschark & Knoors, 2012). Delays in language and literacy development tend to persist into adulthood, resulting in a detrimental impact on world knowledge, independence, and mental health (Hintermair, 2014; Fellinger et al., 2008).

1.2 Early identification and intervention

The individual, social and economic costs of deafness can be mitigated to some extent through early identification and intervention programmes. These are well established in most developed countries but not in LMICs where the incidence of congenital or early acquired hearing loss is estimated to be 6 in every 1,000 births. Inadequate early detection and intervention compromises children’s early linguistic, social, and cognitive development and leaves parents of deaf children (most of whom are hearing with no previous experience of deafness) without early support and guidance (Sass-Lehrer, Porter & Wu, 2016). This is often compounded by a shortage of education and health professionals and limited access to education and health services. These issues are exacerbated in contexts where the experience and implications of being deaf are not fully understood or are stigmatised, and where approaches to accessible spoken and sign communication have not been socialised (Störbeck & Young, 2016).

The impact of deafness on the fundamental facilities of language and communication can therefore have far reaching consequences for basic human rights, mobility, employment, education, and health. For young deaf children and their caregivers, the emphasis on early care and education is thus paramount as the only effective way to mitigate the language, communication, and wider developmental impacts of childhood deafness. These contextual factors challenge the delivery of the United Nations sustainable development goal (4.2) to provide quality early childhood development, care, and pre-primary education for all and also compromise the rights of deaf children to be protected from discrimination, to be educated and thus enabled to become independent participants in society (UNICEF, 2009).

1.3 Research into early development and support

To shape early years provision in different parts of the world requires an understanding of the local educational and health infrastructure and resources as well as the social and cultural
expectations of early development and care. Research into the early development and support of children who are deaf, and their families in LMICs is virtually non-existent and contextual constraints inhibit engagement with the published research of the deaf education and deaf studies academy (centered on USA, Canada, Australia, UK, Scandinavia). The development and communication of knowledge in this area is thus western-orientated and predominantly based on anglophone research and evidence-based models of intervention and support (Knoors et al., 2019).

The current consensus statement on the essential principles that guide family-centered early intervention with children who are deaf (Moeller et al., 2013), is largely informed by research from Europe, USA, Canada, and Australia except for insights from the South African context (Störbeck & Calvert-Evans, 2008) and the Global Coalition of Parents of Children who are Deaf or Hard of Hearing¹. Despite extensive efforts by this panel of experts to develop an inclusive set of principles, the guidance is underpinned by assumptions, values and social constructs of, for example, childhood, education, parenting and inclusion that reflect western, industrialised and economically rich societies. In placing family-centred practices at the heart of early intervention and support, this statement acknowledges differences between families but is less agile in terms of recognising different cultural expectations and understandings of family interaction and relations, parenting roles, self-advocacy, and the possibilities of engagement in decision-making.

Within this statement best practices for early support and intervention are predicated on early and timely access to newborn hearing screening for all families. (Yoshinaga-Itano, 2013). The model of early support proposed is built on trusted reciprocal and equal family and provider partnerships that facilitate autonomy and informed decision-making. Concepts of self-efficacy are highly valued as are parent-led support networks and connectivity. Implicit within this

¹ This is an international collaboration of parent groups dedicated to promoting improved protocols and practices which enable informed choice and the empowerment of families with a deaf child throughout the world.

https://www.gpodhh.org/
statement is an assumption that there are universally shared understandings about the value of interaction, the importance of a rich language environment and optimal opportunities for language learning, and the accessibility of different hearing technologies. The knowledge base for early intervention and support is recognised as crucial and it is assumed that trained qualified providers will have the requisite skills and knowledge to support child development and family well-being.

Economically rich countries have thus driven the development of early hearing detection and intervention policy. Insights from wider research into disability in the Global South suggest that a more inclusive set of principles would need to take account of different cultural models of child development (Morelli et al., 2018) as well as the relevance of a strong collective culture and emphasis on community and extended family networks (Kabay, et al., 2017, Singal and Muthukrishna, 2014), and an understanding of the societal goals of adults (Myers, 1992).

1.4 The research context

The context for this research study is Ghana where the goal of inclusive and quality education for all is part of the Government reform agenda and a recognised area of need (Wolf et al. 2019). In Ghana there is a developing infrastructure for coordinated education and health services for deaf and other disabled people. Ghana has a developing Sign Language (GSL) and an active National Association of the Deaf (GNAD) that campaigns to reduce the social isolation and marginalisation of deaf people (Nyst 2010, Opoku et al., 2020). However, the early support of young deaf children and their caregivers is an unmet need (Oppong & Fobi 2019). Ghana has no national newborn hearing screening programme, diagnosis of childhood deafness is typically late (20% of children are not identified until after their fifth birthday) and there is no established cochlear implant programme at this time. Hearing screening mainly takes place at regional centres through behavioural testing after referral. Over 80% of children are identified before their third birthday but this is still suboptimal compared with the objectives of screening within the first eight weeks of life. There are financial and human resource issues in relation to early diagnosis; in a country where over one million people have a hearing loss there are only 10 trained audiologists and 64 qualified teachers of the deaf.
There are no early years programmes for deaf children although some schools and clinics offer preschool language and communication support to families. Where available, this support focuses on preparation for kindergarten and school and the development of spoken and sign language. However, in Ghana as in many other African countries, non-enrolment in pre-school programmes is common and can be as high as 70% where parents fear prejudice and stigmatisation and prefer to shield their deaf children from society rather than disclose their deafness. In the consensus guidelines, parents are encouraged to engage in collaborative training and parent-to-parent support, but most do not see themselves as legitimate collaborators or advocates for their children’s education (Oppong, 2003). The engagement of caregivers is thus problematic especially in rural areas where incidence of deafness is higher than average.

Similar descriptions are provided from other LMICs including several other SSA contexts (Ethiopia, Nigeria, Namibia, Kenya, Tanzania), India, and Sri Lanka concerning late identification and the lack of widely accessible early educational programming (for full reports see Knoors et al., 2019). The lack of systematic newborn hearing screening in all cases delays intervention and support. The geographical inaccessibility of the available support for many families and the dearth of trained practitioners means that young deaf children miss out on a preschool experience and parents do not get the professional or peer support and encouragement that they need in the early months and years of their deaf child’s life. Within these reports there are some good examples of established public interest groups and the ways in which they can make a difference by improving public awareness, promoting the use of national sign languages, empowering parents, training practitioners, and providing forums for support and information. Such groups are however generally not state-maintained but supported by NGOs, parent organisations, church communities and charities.

Ghana is a multilingual and multicultural country where more than 40 languages and many more dialects are spoken. English is the official language, a legacy of Ghana’s colonial history, but there is ongoing policy debate over the use of English and home languages in schools (Bronteng
et al., 2019). In Ghana, indigenous sign languages ² and the use of home signs ³ existed before the establishment of Ghanaian Sign Language (GSL). The development of GSL as a national sign language was initiated by American missionary work in deaf education in the 1950s when it is thought that American Sign Language (ASL) began to be used in schools for the deaf alongside indigenous signs (Kiyaga & Moores, 2003). GSL does not have official status as a language in Ghana but is used in education, the mass media and all urban events or meetings for sign language interpretation. Recent linguistic research into GSL has facilitated the documentation of phonology, morphology, iconicity, syntax (Edward & Akanlig-Pare, 2021), there is a fully developed smart phone-enabled dictionary (Azutiga et al., 2015) and on-going developments in interpreter training (Oppong et al., 2016). However, negative attitudes towards the use of GSL are reported; few hearing people are inclined to learn GSL because of the stigma attached to deafness as a disability (Baffoe, 2013). There is limited societal understanding of what it means to be deaf and a lack of awareness of the communication possibilities of signed languages (Opoku, 2020). GSL is the medium of instruction in schools for the deaf but beyond these contexts there are few opportunities for caregivers to learn sign language. The resulting communication barriers between deaf children and their caregivers is a cause for concern in the education sector and a source of parental stress (Opoku et al., 2020).

The north-south translation of policy and guidelines thus needs careful contextualisation in terms of social, as well as resource issues. Olusanya & Newton (2007) report that in many countries of the south, parental understanding and education are key factors in the development and uptake of early detection and support services. At the same time, in their survey of 18 LMICs, they also found that the beliefs and attitudes of the community around the family were inhibiting factors in terms of parental behaviour. To shape the early care and support of deaf

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² The existence of Adamorobe Sign Language (AdaSL) and Nanabin Sign Language (NanaSL) has been documented by Nyst (2010).
³ ‘Home signs’ describes spontaneous gestural communication used within families who do not know a conventional sign language (Mylander & Goldin-Meadow, 1991).
children beyond European and North American models there is a need for research that examines different care and education values and practices at the levels of family, community, and society that incorporates the lived experiences of caregivers (Kabay, 2017, Marfo et al., 2011).

2 Research questions

This research is concerned with the sociocultural resource dynamics of the early support and care of deaf children and their caregivers in an LMIC such as Ghana. We aim to identify and describe the existing precarities and available social and material resources surrounding early support, the intersecting influencing factors and the potential for change and development. Through collaboration with education and hearing-health professionals and work with caregivers, families and communities, we will develop critical understandings of the social and resource contexts of young deaf children to support the development of early years policy and practice that can be replicated across different urban and rural contexts.

To achieve these aims, the project team are working with schools for the deaf, rehabilitation centres, deaf communities, and families of deaf children to investigate the contextual and social understandings of childhood deafness, early years development and responsive caregiving. We are gathering knowledge about the proximal relationships among children, families and communities, and their interaction with education and health environments, deaf communities, and the wider cultural context. We plan to use these insights to identify contextually sensitive ways of working with the available resources within and without the family to mitigate the developmental precarities of childhood deafness. We will translate this knowledge into support resources for caregivers and training materials for education and health practitioners.

3 The research team

This research is led by the UK Principal Investigator (University of Leeds) and two Ghanaian Co-Investigators (University of Education, Winneba), who have deaf education and clinical experience. The work across these two institutions and two countries is coordinated by the
Project Officer (PO), who is a professionally qualified Ghanaian Sign Language (GSL) interpreter with experience in audio and video transcription in the Ghanaian deaf education context. The team of three Ghanaian Research Assistants (RAs) are all qualified teachers of the deaf with post graduate research experience. Two of the RAs are professionally qualified GSL interpreters. During the second year of the project, three deaf leaders joined the project team to support the work with parents, professionals, local communities, and policy makers and the communication of the findings.

4 Recruitment and participants

Participants were recruited from Southern, Middle and Northern sectors of Ghana. We approached the three schools for the deaf in the southern, middle and the northern belt of Ghana (Mampong Akuapem in the Eastern region, Jamasi in the Ashanti region and Savelugu in the Northern region) and the speech and hearing assessment centre of the University of Education, Winneba and the Salvation Army Rehabilitation Centre at Agona Duakwa in the Central region of Ghana. The heads of the schools and the centres invited the parents for a short briefing on the project that was given by the local project team, after which caregivers were invited to take part in the interviews. Interested caregivers were then contacted through phone calls. The aim and objectives of the interviews were explained, and initial permission sought from parents for participation.

The RAs and the caregivers negotiated a preferred date, time, and venue for the interview. The language of communication for the interview was specified by the caregivers and included Twi, Fantse, and English. On the day of the interview, the consent form was read and explained to caregivers by one of the RAs in the preferred local language, after which caregivers were asked to affirm their agreement by signing or thumb printing. A second RA conducted the interview, and the third RA took notes. All the interviews complied with the Ghana COVID 19 protocols and lasted for 45 minutes. The RAs transcribed the interview directly into the local language after which, a transcription in English was prepared.

In total, 12 caregivers came forward to participate in the interviews including eight mothers, three fathers and one grandmother with children between the ages of 5-15 years. Due
to late identification and lack of reporting it was not possible to recruit parents of preschool deaf children. Five of the dozen participants were single parents. Three of the interviews were conducted in spoken English, six were conducted in Twi, two were conducted in Fantse, and one in blended English and Twi\textsuperscript{4}.

\textsuperscript{4} Codeswitching between Twi and English is common in everyday interaction in Ghanaian society (Arthur-Shoba, J., & Quarcoo, M. 2012).
Table 1. Participant overview

<table>
<thead>
<tr>
<th>Caregivers</th>
<th>N = 12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship with child</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>8</td>
</tr>
<tr>
<td>Father</td>
<td>3</td>
</tr>
<tr>
<td>Grandmother</td>
<td>1</td>
</tr>
<tr>
<td>Location</td>
<td></td>
</tr>
<tr>
<td>Ashanti region</td>
<td>3</td>
</tr>
<tr>
<td>Central region</td>
<td>4</td>
</tr>
<tr>
<td>Greater Accra region</td>
<td>4</td>
</tr>
<tr>
<td>Eastern region</td>
<td>1</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>No formal education</td>
<td>1</td>
</tr>
<tr>
<td>Basic level (primary and junior school)</td>
<td>7</td>
</tr>
<tr>
<td>Secondary</td>
<td>1</td>
</tr>
<tr>
<td>Tertiary</td>
<td>3</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
</tr>
<tr>
<td>Trader</td>
<td>4</td>
</tr>
<tr>
<td>Semi-professional</td>
<td>5</td>
</tr>
<tr>
<td>Professional</td>
<td>3</td>
</tr>
<tr>
<td>Age of deaf child</td>
<td></td>
</tr>
<tr>
<td>5-10</td>
<td>9</td>
</tr>
<tr>
<td>11-15</td>
<td>4</td>
</tr>
<tr>
<td>Sex of deaf child</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11^5</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
</tr>
</tbody>
</table>

^5 The higher reported incidence of deafness among boys is consistent with other studies in Ghana, for discussion see Adadey et al., (2019).
5 Data collection: Interview schedule

For each caregiver, we collected brief biographical information at the start of the interview including details of their education and employment. The caregivers were asked about the home and family context and invited to give details about their children and their deaf child/children. We also asked about the community around the child and family and the relationship between the community, the family, and the deaf child/children.

We asked about the different languages used in the home, the different ways in which communication took place among the family members, and strategies used to engage with their children in different activities in the home. We offered prompts in relation to the use of spoken and signed language as well as multimodal strategies (gesture, pointing, demonstration, touch). This included asking about the availability and use of hearing technologies at home.

The caregivers were invited to share their experience of identifying their child’s deafness, and the role of other family members in noticing hearing loss. We asked them about the involvement of different professionals from the clinical and educational contexts and about their access to parent support groups, deaf adults, and mentors.

Our questions about the available support and experience of intervention sought to establish the means of help for parents from any source such as family, community, preschool, clinic, or other agencies. We asked about caregiver approaches to supporting their child’s development and learning and invited them to share what worked well and less well. We invited caregivers to talk about what kinds of additional support they would have liked and included a question about the kinds of collaborations that would help them to support their child’s development and learning.

6 Data analysis

We applied a staged thematic approach to the analysis of the interview data (Braun & Clarke, 2006). We were conscious that as a team we were engaging in cross-cultural interpretation and so we worked together to build the coding instrument. Each of the team members reviewed the transcribed interviews independently and then we discussed each one as a team. In these
meetings we invited each other to challenge perspectives, add context and zoom closer into both the lives of the participants and the cultural context of the data. We then integrated these perspectives with the relevant etic knowledge around early development and support. To get underneath the realities and, as far as possible, to mediate our own interpretations, we discussed the content of the interviews and the use of language by participants.

We were concerned not to let the translation process obscure the original responses (Temple, 2002). The language of the participants was used by the researchers who are linguistically and culturally competent. We worked with each transcription to ensure conceptually accurate translations of the participant (Temple & Young, 2004).

The analysis process was completed over a six-month period. During this time, weekly RA and whole team meetings took place on-line to review interview material and develop consensus around the interpretation of participant responses, the assignment of thematic categories and the identification of main and sub-themes. This process resulted in a coding handbook that could then be used by all team members to further analyse, describe, and report on the interview data.

Using the coding handbook interview transcripts were marked up individually and then we met on-line as a full team to agree the assignment of the a priori codes and the emergence of any new themes. Through further review of the interview extracts, and where there was the need to return to the full transcripts, we undertook a fine-grained breakdown of the main themes to identify sub-themes and their frequency. This was an iterative process that involved small group and whole team meetings to review, discuss and contextualise different interpretations of interview extracts.
<table>
<thead>
<tr>
<th>Main themes</th>
<th>Sub-themes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Encountering and overcoming difficulty</strong></td>
<td>• Caregivers had a negative reaction to having a deaf child</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>• Caregivers have prior knowledge about deafness</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>• Caregivers sought a cure for their child’s deafness</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>• Caregivers have financial worries</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>• Caregivers refer to faith as a part of the acceptance process</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>• Caregivers experience negative reactions from others</td>
<td>7</td>
</tr>
<tr>
<td><strong>Communication strategies and expectations</strong></td>
<td>• Homes where more than one language is spoken</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>• Caregivers learn and are using sign language</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>• Caregivers unsure about the use of sign language</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>• Caregivers think that their child will use speech</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>• Caregivers think that their child will not use speech</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>• Caregivers use multimodal communication strategies</td>
<td>12</td>
</tr>
<tr>
<td><strong>Sources of early support</strong></td>
<td>• Caregivers supported by other parents of deaf children</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>• Caregivers received support from schools</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>• Caregivers supported by the Church</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>• Caregivers supported by other groups and NGOs</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>• Caregivers supported by wider family and community</td>
<td>2</td>
</tr>
<tr>
<td><strong>Caregivers as early educators</strong></td>
<td>• Caregivers try to support their child’s learning at home</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>• Caregivers seek help with their child’s learning at home</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>• Caregivers want their deaf child to be well educated</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>• Caregivers have high expectations for their child beyond school</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>• Caregivers feel empowered to get involved with their child’s learning</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>• Caregivers feel disempowered and unable to get involved</td>
<td>2</td>
</tr>
</tbody>
</table>
7 Participants

To protect the privacy of the participants and anonymize their responses we refer to them as Caregiver 1-12 and shorten this to C1, C2 throughout the text.

Caregiver 1 is a mother who is married with three children. She is from the Ashanti region. She has two deaf children who are second and third born. They live in her husband’s family house with her sister-in-law. C1 was educated to basic school level and is a small trader and her husband does casual work. This interview was conducted in Twi.

Caregiver 2 is a father, who is married with three children. He is from the Ashanti region. C2 has one deaf child who is the second born. The family live in their own house and have two tenants. C2 was educated to basic school level and is an auto mechanic. This interview was conducted in Twi.

Caregiver 3 is a single mother, with five children. She is from Central region. She is a small trader and has never been to school. C3 was educated to basic school level and is a food seller. She has one deaf child who is the fifth and last born. This interview was conducted in Twi.

Caregiver 4 is the mother and single parent of one deaf child. She is from the Central region. They live in the family house with her mother, sisters and brothers. C4 was educated to basic school level, and she is a hairdresser. She has her own hairdressing salon where we interviewed her. This interview was conducted in Fantse.

Caregiver 5 is a father and a single parent of two children. He is from the Central region. His first-born child is deaf. C5 has an undergraduate degree in health administration and education, and he is a lab technician at a Hospital at Winneba. This interview was conducted in English.

Caregiver 6 is a mother who is married with three children. Her first born child is deaf. She is from the Greater Accra region. C4 has a Master’s degree in public health and is a senior nursing officer at a hospital in Accra. This interview was conducted in English.

Caregiver 7 is a mother and a single parent of two deaf children. She is from the Greater Accra region. She has a basic level of education and works as a waitress in a hotel in Accra. This interview was conducted in Twi.
Caregiver 8 is a mother who is married with three children. The first-born child is deaf. She is from the Greater Accra region. C8 was educated to Secondary School level and works as a small trader. This interview was conducted in blended English and Twi.

Caregiver 9 is a mother who is married with three children. She has one deaf child who is the third born. She is from the Greater Accra region. C9 has a Master’s degree in pharmacy and works as a pharmacist. This interview was conducted in English.

Caregiver 10 is a mother of three children. She is from the Central region. Her first born child is deaf. C10 was educated to basic school level and is a small trader. This interview was conducted in Fantse.

Caregiver 11 is a father who is married with two children. He is from the Eastern region. His first-born child is deaf. C11 is educated to basic school level and is an auto mechanic. This interview was conducted in Twi.

Caregiver 12 is a grandmother of one deaf child. Her grandson is the only child of his parents. C12 is from the Ashanti region. She has no formal education and is a farmer. This interview was conducted in Twi.

8 Theme 1: Encountering and overcoming difficulty

Caregiver initial negative reactions and responses to having a deaf child are strong themes across all the interview data. Caregivers talk about their difficulties in accepting their child’s deafness and their personal feelings of sadness. They describe the experience of being in unfamiliar territory, encountering new decisions and how they make sense of their situation. Some parents talk about seeking a cure for their child’s deafness and many describe the sustaining importance of faith and prayer. Caregivers are also troubled by external burden of financial hardship and the social pressures of discrimination and negative reaction from others.
8.1 Acceptance

All 12 of the caregivers describe a negative personal reaction to having a deaf child such as difficulties with acceptance, sadness, grief, and guilt. This response was usually linked to their concerns over communication.

So, I don’t accept that he is deaf and can’t hear or talk. C4

Caregivers describe the sadness that they feel about and for their deaf child along with expressions of shame and guilt of having had a deaf child.

(…) sometimes I become discouraged and sad for giving birth to a child like this. C4

Sometimes he gets bored and isolated when he cannot hear and move with other hearing children, and I become sad when I see him in that mode. C4

It is very shameful and difficult when you see that you have given birth to a child who cannot hear at the beginning. C2

Caregivers look for a reason that their child is deaf. The mothers reflect on their pregnancy and on what could have influenced the birth of a deaf child.

Initially, I wanted to find out if I did something wrong. I took some medications. I was thinking a lot and I also realized that it was not helping so what we had to do was to look forward and conquer and overcome. C9

When my child stopped talking at a point she couldn’t hear, I cried. I felt like why is this happening to my child? What have I done wrong? Because I am nurse and I attended my antenatal everything that I needed to do as an
expectant mother, I did so why is this happening (...) and that guilt was so heavy on me. C6

This level of anxiety and guilt is very affecting for caregivers who may struggle with their health as a result, and at the same time as learning to care for a new deaf child.

I really grew lean. I was always thinking so much (...) talking to people was even difficult for me. I never wanted to meet or talk to people. C1

Caregivers talk about overcoming the sadness though a process of acceptance.

As time went on, I accepted the fate of the child because I felt it had happened and there was nothing to overturn it so I rather directed my attention to how I could raise him to be useful to the society rather than to think daily about his plight. C8

As a part of this process caregivers try to rationalise what being deaf means for a person’s life, for their inclusion in society, and for themselves as the caregiver with a responsibility to raise their child.

I know it is not the end of life. Deafness does not mean disability. You can still work it up and become who you want to be. So, when I identified it, it didn’t matter and didn’t worry me much but I think that the onus now lies on me to ensure that my child becomes what I want him to become. C5

Part of the acceptance process involves changes in expectation around language development. Most of the parents talk about their hope that their child will speak and thus eventually will be able to take their place in society.

I expect people who are in position to help my sister to raise Eugene to become a
responsible person in the society and more importantly restoration of his speech. C3

They want their child to be able to do well in the world, and to be independent but this is often predicated on ‘getting back’ speech, or eventually learning to talk.

I hope that my girl will become a very prominent person not only in Ghana but in the whole world. Because I want her to be a benchmark up there so that parents will get to know that there is ability in disability. (...) So my hope for the child is so big when she gain her speech, it is fair and good and when her hearing improves, it is fair and good. C6

Caregivers talk about the ways in which they grow to accept their child’s deafness, and communication, and they stress the importance of showing that acceptance.

We shouldn’t neglect them or discriminate against them. They might be great people to the family or nation in future. (…) We do not neglect him because he cannot hear or talk. C12

One mother looks back with hindsight on her first hopes about spoken language as unrealistic.

I doubted and had the belief that the speech would come later on. That was my childish thought at the time. C7

8.2 Making decisions

Another aspect of the acceptance process is linked to decisions about schooling. Sending a child to a school for the deaf is part of the process of accepting their deafness. One caregiver explains that the pain of doing this and taking their child to the school was as much about facing up to their child’s deafness as the separation itself.
I initially didn’t accept that the child had that disability. It was upon persistent persuasion that I finally accepted their condition and decided to heed the advice of other people. The day I was sending my boy to Mampong, I cried throughout the journey. The boy didn’t know what was making me cry. He thought his leaving the house was the cause of my crying but there was something painful in me that made me cry but not his leaving. C7

When caregivers talk about these decisions there seems to be a dichotomous understanding of educational choices and the outcomes for sign and spoken language: A school for the deaf means they will use sign language and mainstream school means they will use spoken language. Caregivers thus worry about sending their child to a school for the deaf and the implications of this for spoken language development.

Some of them advised us to withdraw from the normal school and take him to the school for the deaf but we knew he would speak so we did not listen to them (...). He is not deaf. I thought sending him there was going to complicate his hearing disability more. C3

(...) I am a bit disturbed because I was told if I send him to deaf school, he might lose the little speech he has because the schools for the deaf only use sign language and gesture as their mode of communication, but I also want my son to talk. C4

They perceive the local and mainstream option as the only way to continue their spoken language development.

(...) I take her to the normal school to interact with her peers and perfect her speech. C7
8.2.1 Search for a cure

Five of the 12 caregivers try to find cures for their child’s deafness. The use of traditional and alternative medicines is common both in Ghana and in other LMICs where there is limited access to healthcare services, especially in rural areas (Kpobi & Swartz, 2019). Caregivers seek cures, often dispensed by elders in the community or family, that include the use of herbal medicines and body piercings.

A lot of people including herbalists took our money and other things all with hope that they could help him talk but all failed. So, we decided to take him to school for the deaf at last. C4

Caregivers also seek a cure through their faith, they talk about using prayer and hoping for miracles.

I have prayed to God to open his ears and make him talk for me. C4

8.2.2 Faith and spirituality

Although some of the caregivers consult with traditional healers, all of them have a Christian religious stance and 7 of the 12 caregivers specifically refer to their belief system as part of their coping strategies. Kara & Harvey (2017) found a similar approach to religion in relation to parenting a deaf child with Black South African hearing mother of deaf children. Caregivers in both studies talk about the role of faith in making sense of their situation, and in enabling them to accept what they describe as their ‘fate’ in having a deaf child. They describe their circumstances as ‘God’s work’ and their faith as a source of strength.

The Lord who gave you that deaf child will give you the wisdom and the courage to take care of your child. C1
The respondents describe having a deaf child as part of a higher intention and purpose that does not have to be fully understood, but that needs to be embraced with trust and patience.

We need to have patient no matter who they are and pray for them so that God’s intention and purpose for creating them can be fulfilled. God knows what is best C12

They see their children as God’s children and as such a blessing for the families. Personal or inner strength comes through their faith and prayer and offers a wider connection with benevolence and tolerance.

Acceptance, I always say God is a God of diversity. C4

The support of the Church can also be quite practical and several of the caregivers mention the Jehovah’s Witnesses as a group that welcomes deaf children and their families and teaches sign language.

Traditional spiritual beliefs within this society can exert a negative influence on caregivers and their experience of having a deaf child. There is a prevalent narrative in traditional Ghanaian society and in other SSA contexts that deafness is curse on the family or local community, that it is the work of witches or vengeful Gods, and as such, a punishment for wrongdoing (Kusters, 2015, Mugeere et al., 2015). Through spiritual leaders, caregivers are sometimes advised to abandon their deaf child who is seen as unnatural or inhuman.

One pastor said my child is not a human being, it was a water baby therefore I don’t need to stay with that child. Seriously I carried the child in my womb for nine months how can the child be a water baby? (…) I am not water woman and my husband is not so how can I give birth to a water child? C6
Despite the evident cynicism in this comment and the general preference of caregivers for a Christian stance that advocates forbearance and acceptance, caregivers are still vulnerable to traditional aspects of African folklore that demonizes disability in general.

8.3 Knowledge and understanding

Of the 12 caregivers that we spoke to, only two had previous experience of deafness. Caregivers are therefore dealing with new experiences of parenting, unfamiliar decisions about schooling, additional financial burdens, and societal discrimination with little or no understanding of their child’s deafness and what this means for development and different communication possibilities.

Caregivers’ understandings of the audiological issues are rudimentary. There is no early screening or guidance and so they rely on their own or family/community knowledge and experience. Recognizing that their child is deaf is often serendipitous.

Even I myself I didn’t recognize but one of my friends said that [name] does not respond to any call made to him C5

Some caregivers report that the first difference that they notice is that their child does not speak. They do not always immediately associate this with deafness but suspect other illnesses or physical difficulties.

We decided to go to [Teaching Hospital] to check whether he was sick or if there was something under his tongue. C1

In describing their interactions with the clinical context, they demonstrate a limited understanding of the nuances of audiological testing and the functioning and possibilities of hearing technologies.

We were hoping that he could talk that is why we didn’t bother to get him a hearing aid. C12
As novices with hearing aids, caregivers do not understand the importance of consistency or how to support their child to make best use of and look after the devices. One of the caregivers reports that their child had difficulty using the hearing aids because they caused them pain (C4). Without understanding the elevated perception of loudness that can occur with hearing aid use caregivers tend to turn the hearing down. This reduces the benefits of the device and children eventually stop wearing them.

Caregivers are also subject to misinformation about deafness and how it can be cured. One of the caregivers described advice about removing phlegm around the child’s heart to help him to talk. As this operation was unsuccessful, they then went to see another man who said he would give the child medication and food so that he could talk. They say that they did this two or three times but that it did not work (C12). Three of the caregivers referred to the common practice of having a small cut made under the tongue to facilitate speech.

We were told that babies have some lines or animal under their tongue which I don’t really know about that so we took him there so that line or animal could be removed C12

But one doctor at the hospital (...) told me the truth that my son is deaf. He said there is an additional line to line under his tongue so he can never talk C10

There is also only partial understanding around communication issues and possibilities. Being deaf is immediately associated with not being able to talk, and this is the main concern of all caregivers. One parent acknowledges that a little bit of knowledge about education made it easier to accept their child’s disability.

6 In most communities in Ghana, there is a traditional believe that deaf people are unable to talk because of their lingual frenulum (tongue-tie) and so when cut deaf people will talk. Some communities believe these ties are animals and should be removed to facilitate deaf children’s speech.
When I got to know that he was hearing impaired, though I wasn’t that happy but because of the little knowledge I had in special education, I felt like he is having an impairment and that is not a disability so I trust he will still pick it up and he is very intelligent, so I know he will definitely pick it up. So I was cool, I was calm with it. C5

8.4 The acceptance and empathy of others

The different caregiver responses to having a deaf child; the mixed feelings of grief, sadness, guilt and shame and the personal resources that they draw on, need to be understood within the socio-cultural context of this experience. The subjective burden experienced by the parents is strongly influenced by external factors. Important among these is ways in which other children and adults respond to their deaf child and their experience of stigma, exclusion and inclusion in their community and the wider societal context. Seven of the caregivers talk about other adult’s behaviours and the problem of being singled out as different, and what it takes to continue to feel confident as parent.

In the community the major problem we have is stigma. Usually when you have a child with disability people look at you in certain way and therefore for your child if you don’t take care the self-confidence will be broken because they point fingers all the time at you and when that happens it becomes a problem. C6

Caregivers want acceptance from others and talk about the barriers in the community and the stigma of deafness as associated with not being able to become educated and have a job.

I want the community to accept any child who has that problem. They are also like us just that some normal persons look down on people with disability. They think they don’t even deserve to have a living. C8
They offer what they have learned to other parents about accepting their child and looking to the school for the deaf instead of leaving their child in an isolated mainstream context.

But I tell them to accept and allow the child to socialize with others because giving birth to a deaf child does not mean he is not a human being. They are also human and can do anything as every human. C2

Caregivers feel supported by meeting other parents with deaf children.

I have come to realize that it is not something designed for one person but it can happen to any person. So, when I meet persons in that condition it gives me consolation that I am not the only person in the soup. Whilst I am crying over my own another person is equally lamenting on his own. C8

Caregivers are sensitive to other people’s expressions of sadness and this, like pity, is more disempowering than supportive and they try not to be affected by it.

People were asking we should send him for prayers. I didn’t give them the opportunity. C9

Sometimes people become sad and feel so sorry for him whenever I go out with him because he is not able to respond to what they ask him. it makes me sad when it happens like that but he is always happy as we are. C12

Others have found the community supportive of them and their child.

Yeah, one thing is that, most of them are very understanding and if he is doing something because they know he is hard of hearing, sometimes they are not too hard on him and if he misbehaves, they have a way of drawing his attention to that. So in terms of communication, the community has been helpful by just being understanding to them C5
They want the community to understand their child and to respond to them as they would like any other person.

The society in general should also understand him, communicate with well him not like maybe they will use him as benchmark to humiliate him or something. C5

Caregivers also talk about the difficulties of allowing their child to socialize with other (hearing) children and the risk of being teased or bullied. Sometimes the harassment that they describe (from other children) is quite extreme and they have to make decisions about exposing their child to such behaviours or keeping them isolated.

It is very difficult though, but you have to allow him to go out and play with others. Even though some may beat or discriminate against him, but you can’t also hide or keep him in the room all time. You just have to be patient and advise your child about those he plays with because he will definitely go out and pay with them. Sometimes I get scared when I see how they beat my child but what can I do? You just have to exercise some patience and talk to them about your deaf child. C4

Some caregivers prefer to keep their child inside and protect them from such behaviours

I will advise the parents not to allow their deaf child to socialize or make friends because they will stigmatize against him and even call him “mumu” [deaf and dumb] just like how it is happening to my deaf son but for my son he doesn’t care. C10

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7 There are diverse views about the concept ‘mumu’ among the deaf community in Ghana. Whereas some think it is the meaning of deaf (in Akan language), others think it is derogatory. Literally, ‘mumu’ means unable to talk.
Among these negative experiences there are also instances of inclusive attitudes from other children and adults, and childhood friendships that enable shared activities and companionship.

Oh, she goes out to play all the time. As we speak, she just took her bath and is about to go out. One of her friends is running an errand for her mother and the friend asked her to accompany her. They are going to grind corn at the corn mill. C1

The responses of others can place an external burden on parents who already have their own emotional responses to deal with. Negative responses from others seems to centre on the difficulties that people have in encountering deafness, perhaps for the first time and, more broadly, understanding difference, and imagining other ways of being (Mackenzie & Scully, 2007). One caregiver touches on this as she describes the importance of sympathy from others and how this has come about, in her case, from personal experience.

When I had not given birth to a deaf child, I felt so sorry and sympathy for parents with deaf children. There was one woman staying close to where I was. She had a deaf child and anytime I meet her, she complained a lot having a deaf child and I felt so sorry for her. But when I gave birth to two deaf children, I really understood her pains and sufferings. I realized that, true it is very painful and difficult in raising a deaf child. C1

While it is not always possible to step into the shoes of others in the way that this parent does, empathetic imagining can help us to ‘expand the scope of our sympathies’ (p. 338) and engage with the experience of another. The challenge in this context is to develop this imagination at a

Therefore, the context in which it is used suggests how one interprets it, whether derogatory or as description of the person.
societal level so that children and adults with no prior experience of deafness can engage with caregivers’ experience with compassion and respect (Nussbaum, 2006).

9 Theme 2: Communication strategies and expectations

Our discussion with caregivers about language and communication centered on the languages used in the home and proximal community, and the communication strategies of deaf children and their family members. Caregivers shared their expectations and concerns about spoken and sign language development and their hopes for their child in the future. The multilingual nature of Ghanaian society, especially in urban areas, is reflected in the language diversity across our sample of 12 participants. More than five languages are used in total across our caregiver sample including Twi, Ga, Fantse, Dagbani, Kokomba, Nanumba, Efutu and English. All the deaf children are in homes where more than one language is used daily.

9.1 Communication strategies

Caregivers talked to us about their interaction with their deaf child in general. They referred to their use of spoken, written, and signed language and described the different multimodal strategies used in the home and community for communication. Most of the parents talked about the way in which they blend the use of spoken language with home signs to make meaning. They expressed doubt about the use of their own sign systems, as not being a recognised sign language.

We only use the Fantse to communicate with him by raising our voice and then sometimes adding signs to it some of the common signs. None of us knows how to sign like the proper sign language but common things like water and stuff the way we use our hand and stuff is common. But most often when you call and at least if you amplify your voice a little, he is able to hear. C5
They integrate the use of verbal and non-verbal strategies ‘speech together with gestures and signs’ (C12). In their use of spoken language they talk about slowing down, exaggerating, and amplifying their speech, and sometimes reinforcing this with writing.

I try to let him repeat the word, or I write on paper, or I give him, [name] go and buy me Frytol, I will give him the bottle. But I want him to be confident, so I try to let him pronounce F...r...y...t...o...l and he will say Frytol until we get there. C9

In the descriptions they emphasize the need to engage their child’s attention and have eye contact.

When you are speaking, he will look at your lips and is able to grasp what you are conveying to him. C3

The difficulties that caregivers describe in relation to communication and language centre on understanding and being understood by their child, and the complexities of including them in family and community activities.

For now, it’s my desire that there will be a smooth communication between us, understanding each other well but it is not so. C11

It’s difficult. If it’s time for storytelling and you’re telling the story, they are all together and you realize that she is not getting it you must use gestures (...). C6

9.2 The use of sign and spoken language

Of the 12 caregivers, three are learning to use sign language and have some basic skills. The other nine caregivers are aware of sign language. They have not learned to sign themselves, but they would like to. However, the sign language classes are usually associated with the school for
the deaf Parents Teachers Association (PTA) meetings that are held three times a year. Because of the location of the schools, and cost of transportation most of the caregivers are not able to travel for these meetings and there is no local training provision.

I have greatest desire to learn the sign language, but my schedule of work is preventing me from doing so. I have only Wednesday as resting day and perhaps the schools will fix Saturdays as the days for introducing the sign language to parents. I will not be in position to attend. C7

When the caregivers talk about the use of sign language, or signs they are not always specific as to whether they use GSL or their own ‘home’ signs. Given their lack of exposure to GSL, it is more likely that they are referring to their own home sign system. Caregivers demonstrate that they appreciate that there is a difference between their home signs and the sign language of the deaf community, that C3 describes as ‘deaf people’s language’ [mumfo kasa].

I developed our own unique sign language we used to communicate. We didn’t conform to the normal sign language, we included everything together, but they still understood me. They could read from my face expressions and gestures to know excellently what he would be talking about. C7

Caregivers also make this distinction by talking about the official and accepted ‘that is the language of deaf people’ to communicate in Ghana [ɛyɛ mumfo kasa ankasa, C11] and the use of other communication strategies such as gestures and demonstrations that C1 describes as ‘not his school’s signs’ [ɛnyɛ sukụufo sign ankasa].

In their responses about interaction, caregivers often refer to other members of the family or the community and ways in which other people interact with their child. One of the fathers talks about the way in which his child is included in the community because other children have learned to sign.
All his friends have learnt the sign language and can sign when playing with him. I am the only person who can’t sign (...). I am always at work but his mother and other two brothers have learned the sign so they communicate with him in sign language. C2

He describes the way in which the family work together to provide interpretation between the deaf child and his father.

(...) when I am at home and want to interact with him, he will make the sign and his mother or brother will interpret to me and vice versa. C2

Four of the caregivers express anxiety and hesitancy about using sign language with their deaf child. The reason that one parent gives is the concern about being different and isolated.

My husband was not too happy about the idea of him using sign language because there was no one else around who was using sign language for communicating with (...). He tried using sign language in addition to the speech and we did figure spelling at a point. He was interested but was more interested in being like speaking like everybody else. C9

Speaking or communicating in spoken language is the priority for most caregivers.

I want to interact with my child through spoken language as I see other parents communicating with their children in spoken language. C4

In two cases, the reluctance to use sign language comes from the children themselves.

He told me he does not want me to learn the sign language. I really do not know why. He insists I communicate with him in spoken language. In situations, where I find it difficult to get what he is saying. I proposed to him to teach me the sign language but he would not
He speaks now, we use speech. We don’t sign. We tried it at a point, but he wanted to be like everyone else, he wanted to talk. C9

The emphasis on being like everyone else and the suggestion that signing is an alternative to speaking, rather than additional, comes through in these comments. One caregiver (C10) says that she would advise new parents of deaf children that their child will not talk because he is deaf, and that they should learn sign language.

When caregivers talk about the use of spoken language, they seem uncertain as to how to support development and what to expect. They are uncertain of their child’s spoken language abilities and lack understanding about how to foster spoken language skills, other than by raising their voices. There is a focus on speech sounds and the pronunciation of individual words (C6). One caregiver (C6) talks about her child using words or sounds which do not have any meaning (Mostly she tries to fake some words but it come out as meaningless sounds and when she realises she makes those sounds and we do not get her, she actually tries to explain to us) ([Sε wode w’ano no ka na wode sign no aka ho]. All of the caregivers use a range of strategies to interact with their deaf children including actions, gestures, demonstration, painting, writing or drawing.

I use gestures or actions to communicate with him sometimes because I don’t know all sign language. For instance, when he asks for towel in sign language, I am able to show him towel. Again, I make sign to him if I want him to buy pepper, tomatoes, or onions for me and he also understands me. Sometimes I try to give him example of the item I want him to buy for me but he will refuse that and rather prefers to write the name of the item on paper. C1
Caregivers also mention the ways in which they manage other people’s expectations of communication with their child, mediate interaction, and tackle a more general lack of awareness about deafness and communication.

Sometimes when my deaf child tries to communicate with his father and the father is not able to understand him, he ignores the father and comes to me. Whether I understand him or not, I try to give a nod to indicate that I have understood him if not he will get angry with me. So that is how we communicate in the house. C1

People think he cannot hear but when you speak, he is able to hear. Some people do the deaf language sign to him but he doesn’t understand those signs C3

(...), some people will say “ooo your child is stubborn “but I tell them it is not because he is stubborn the thing is if he hears that is when he will react C5

Through the caregiver narratives, the ability to develop spoken language is a strong theme and an area of concern but there is an emerging level of awareness around the use of sign language as a path to success; that you can be successful even if you do not speak.

My hope for her in the future is to do well and possibly talk. If she does not talk and it is through the sign language that will make her to be gainfully employed so that she can make ends meet, so much the better. I would not like her to face difficulties in life in the future C11

I want him to be a prominent person in society. That people will realise that this child could not speak but has been successful in his chosen field, C8

Caregivers in this study use their own strategies in communicating with their deaf child. There is no guidance or policy on communication and an absence of sign language training centres where
caregivers can learn sign language. Most of the caregivers do not know GSL and prefer to use other forms to communicate with deaf children rather than GSL. None of the caregivers have previously met a deaf person in a professional/supporting role. The caregivers that we interviewed are nonetheless focused on making communication work with their child. Their responses universally demonstrate the ways in which they use the resources and repertoires available to them to engage with their child and encourage reciprocal interaction.

10 Theme 3: Sources of early support

Formal early support programmes for families of deaf children that follow up from identification and confirmation are not established in Ghana. Navigating the unfamiliar ground of having a deaf child can therefore be a haphazard experience. The issues that emerged from these interviews about early support centre on the potential sources of support, the accessibility of support and the different ways in which caregivers engage with support possibilities.

None of the caregivers had received any early professional support, outside of routine clinic visits for hearing tests and hearing aids and did not know of any support groups or organisations. It means that the burden of support lies solely with the caregivers.

No help, everything is dependent on myself and the father. No support from the church.
No support from where I live. No support from the school. C6

One of the comments highlights the precarious position that caregivers find themselves in when they receive a diagnosis without full information, and in this case with little humanity or care.

At the hospital, their diagnosis alone can put some fear in you. There were instances they will openly tell you that your child is sick so take him/her to the school for the deaf. They do not at times encourage we the parents. C7

The reluctance of caregivers to disclose that they have a deaf child was a barrier to support in some cases.
I don’t get any support from the church because I don’t usually talk to people about my deaf child. People get to know that my child is deaf when they call him or asked him a question and he is not able to respond to them. So I don’t personally talk to people that I need support or help for my child. C4

Because parents sometimes do not know that their child is deaf, they also miss out on potential opportunities for early support.

It was about four years ago that I heard some people came to the schools to assess the hearing status of the children but they never came again from that time. We didn’t know our child had that problem so he was not taken to them for assessment. C12

Others talk about the incidental advice given to them from the clinical context. This corresponds with what we learned from the practitioner interviews; that they saw their role as supportive as well as clinical/therapeutic.

The centre again advised me to send him to an inclusive school where they use sign language to teach deaf children. C4

For two of the caregivers there were opportunities for support in connection with the schools for the deaf, but this was not available (because of late identification) until their child was of school age. This support was focused on language and communication and specifically encouragement for learning sign language.

Before they were admitted into the school, we (parents) were invited from time to time for training on how to communicate with our deaf children in sign language. C1

The teacher said it would be important for her to learn the sign language to receive
instructions through that language. She is able to say 1, 2, 3 up to 10 but it does not come out clearly. C11

However, this sort of advice does not reach caregivers early enough. Families have developed alternative ways of communicating and find the advice about learning sign language confusing. The support needs to come at an earlier stage, and the use of home signs explained and accepted as an integrated part of the communication repertoire.

As at now, whenever we go to school, they have been asking us to learn sign language so that when the student comes home we can communicate with him. We are learning a little bit by bit, but they don’t understand what we are saying. It is the sign language that we can communicate with him in the house. C8

The support infrastructure around the school, such as through the PTA meetings and contact with other parents, is nonetheless a potential resource that could be expanded, and include other family members.

Two of the parents talked about support from the church where sign language is available.

(...) here we don’t have people who can teach or train us in sign language. But it is the Jehovah Witness people who usually come here to teach them Bible in sign language because they understand and communicate in sign language. C1

Additionally, the caregivers talked about the emotional support that they get from schools, in terms of acceptance and expectations. They cite examples of prominent and successful people who are/were deaf and that gave them encouragement that their child would also attain such ‘distinguished positions’ (C8). They receive personal support from friends and acquaintances with recognition that such support can be passed on among caregivers.

I was advised by one woman to get courage and take my children to the school for deaf. It
really encourages me to do so. So if I also meet a parent in such condition, I will also advise her to be courageous and take good care of the child because you cannot run away from your child. C1

Seven of caregivers had had the opportunity to meet with other parents and one parent received some advice through a family connection.

Ok, one sister staying in the community with us has a deaf child who also attend school for the deaf at Jamasi introduced us to the school. She told us that the school accepts young deaf children and that was the reason why we sent him there. We never knew of any special school for deaf children initially. He was six to seven years when we took him to the school. We were going to the school every month for training for a year before he was finally admitted into the school. C2

Parents expressed interest in meeting with other parents

I would be glad if we can have parent groups in the community to discuss the welfare of our deaf children. I only know of two parents who have deaf children in our community here. C2

When caregivers were asked about support, their concern was often about financial help for hearing aids, school fees and materials. They are disappointed by promises of financial support, for example from the district education office or disability fund, that never materialises.

Oooh I was not given any support. We only meet to discuss about the welfare of the association and collection of dues. they told us that we will get support from the government every month to support our deaf children and that was the reason why I registered to join but later I withdrawn from it because they turned the association into politics and I was not happy about that. C4
Social welfare promised some form of help. There too, you will struggle and be tossed back and forth before your need will be attended to. I think somewhere last year (2020) we were given GH¢1,000.00 to pay part of his school fees. C8

This was clearly an objective pressure for caregivers who talked about the financial burden of trying to do whatever is needed to support their child.

We have to put our money and other resources to push him to realize his dream C3

In addition to school resources, parents also worry about the cost of hearing technologies. For most parents, the cost of hearing aids is beyond their reach and especially modern and digital technologies. Caregivers talk about the insecurity of their finances and the use of loans and the need for permanent work. They speak about other ways in which they have sought financial support including via philanthropic organizations. However, there is also a stigma associated with asking for support and the risk of their situation and their needs being exposed more publicly.

11 Caregivers as early educators

All of the caregivers in this study were preoccupied with their child’s education and their progress in school. They talked about their expectations for their child and how they think their child will do in educational terms. For some caregivers this involved reflecting on their own educational experience, and they express some anxiety around their capabilities in supporting their child’s education and their understanding of what is required.

Among our participants, education in general is valued and caregivers want to find the best options for their child. All 12 of the caregivers express their wish for their deaf child to be well educated. Ten of the 12 parents spoke of their high expectations and hopes for their deaf children in terms of education and the future independence that this will bring.

I think my first deaf child has a great vision and hope and he can go very far with
it. I pray they can get a well-paid government job in future so that they can depend on and support themselves. C1

I would want for my child good education. Go higher in his educational life so that he can become an important person for me in future. C10

Education is described as the way to secure an independent future and employment, notwithstanding the concern expressed about employment possibilities as a deaf person.

I always pray to God for His help and support so that I can work and support my child to reach a higher level in education. Because he is deaf, I don’t know the job opportunities available for him after school. I don’t also know any organization that will employ him for job in future because he is deaf. C2

However, caregivers worry about their child’s education. Where the options available involve boarding school some care caregivers worry about separation from their child, and what this means for the child socially and emotionally,

In my case I was hesitant to take my child to school even when I got to know she had the condition because I felt she was too young. She can’t take care of her daily activities. She cannot even brush her teeth she cannot wash her clothes. She cannot bath properly so let me wait until I actually took a tour to the school because I wanted to ascertain what was happening there. (...) I had to quickly make up my mind because the delay actually doesn’t help. C6

Others see the school for the deaf option as a more secure way of ensuring their child’s engagement with education.
I am not happy with him schooling here because all his friends are at the seashore so anytime he comes back from school, he quickly goes there to play which is not helping his studies. If I can get help to send him to cape coast school for the deaf to stay there and learn, I would be very happy because I heard there is a school for the deaf children. C10

Some caregivers express an unfamiliarity with the educational context and a lack of understanding of the reasons for their child’s learning delay and of the supportive intervention measures. Two parents felt unable to get involved and support their child’s learning.

I don’t know whether he finds it difficult to learn or not because last time I visited him at school, I noticed that all his classmates were done with their class exercise, but he was the only person left behind to finish his work. I asked the teacher to use cane on him because for him if you don’t use cane on him, he won’t learn. C4

Having some educational experience provides caregivers with confidence and agency in their decision-making about school placement. Ten of the 12 parents expressed interest in getting involved with their child’s learning.

No one advised me to take him to that school. The inclusive, the Winneba inclusive school. I took him there myself because I had the opportunity to read special education as general programme, introduction to special education yeah so, I was able to use that knowledge to take him to school. C5

Six of the 12 caregivers talked about supporting their children’s education at home. Their education practices tend to focus on language and communication where they have the most concerns and the greatest lack of experience. Four of the parents sought outside help or peer tutoring for schoolwork and sign language communication.

When he comes from school, he shows his homework to me so that I can help do it. If
can’t be of help, I call one deaf boy who has now completed senior high school to explain and assist him do his homework. C10

(...) if he can get someone who will be there for him, I mean in terms of the signing, sign language, communication and helping him with his school assignment and stuff that is after school tutorials, I will be grateful then. C5

Others find ways of offering support at home for school tasks.

We have bought him same books as the hearing children use at school. When is time to write, the teacher will give him his book and ask him to write what is written on the board into his book. He is able to do what the teacher teaches him. C12

In some areas, he knows already but where he does not know, I write on a piece of paper and explain to him. C3

(...) parents must help their deaf child to do their homework and teach them at home if they can. C4

One parent comments on the steps that they take to support their child’s education, showing an awareness of the importance of visual material for explaining concepts and supporting literacy development (such as in picture books), and the potential of the use of gesture in the home to support connections between spoken words and their meaning. This parent showed awareness of their child’s learning needs (such as a well-structured curriculum) and what accommodation could usefully be made to foster success.

He is very smart. He has a good memory. The curriculum is more reading based. We are thinking of introducing him to something hands on, more practical and if there is something that he can get certification for as well that will really help. C9
This parent also comments on the difficulties that teachers have delivering aspects of the curriculum to deaf children and, based on their own research, shares strategies and resources with the teachers. In this case, leadership from the parents themselves is recognized as important.

I look for tips for teachers. What people do in more developed countries? I print it out and give it to the teacher and explain it. I read about the FM system so I got sponsorship from work, so I was able to purchase FM system for him. Showed the teacher how to use it. I got a tablet for the teacher. So everything has to do what we the family decides to do. Anything you can think of that will help you. But the school, they listen, they are accommodating. C9

In relation to early education and intervention, one of the parents recognizes that the experience of delayed identification and their personal difficulties of accepting the child’s deafness has been disruptive for the child’s learning and development. Another parent expresses frustration with the school system, the support available for young deaf children and the delays to the provision of intervention.

The psychologist encourages us to continue to keep her in a regular school and then get a special needs teacher in the school to help with the child’s progress. But unfortunately, her school doesn’t have a special needs teacher and they also do not have equipment or pay to help teachers to function. It was quite surprising to me that a country such as ours could not subscribe to the universal rights of a child yet still a big school like didn’t have one special need educator. C6

Education is valued by all caregivers but not all caregivers are equipped with the knowledge, skills or confidence to act on this. The caregivers in this study have diverse experiences of education themselves, ranging from no formal schooling to university-level qualifications, and
this diversity is reflected in the economic and employment status across the group. The caregivers with high levels of qualifications and professional employment are better positioned to engage with educational decision-making and support and are more confident in asking questions and seeking advice.

12 Discussion

12.1 Expectations of early support

Having a deaf child can be life changing for caregivers who have no previous experience of deafness, limited understanding of the developmental and educational precarities, and who are unfamiliar with the potential of sign language and the deaf community networks. There is a lot to learn about language and communication, decisions to be made in relation to technologies, support services and education, potentially new financial pressures, and perhaps changes to family behaviours and interaction. The culmination of these new caregiving demands is potentially stressful for parents in a way that can influence their child’s social-emotional development and wellbeing (Hintermair, 2006, Quittner et al., 2010).

There is international consensus that early professional support for young deaf children and their caregivers should be a prompt and holistic process that recognizes families’ strengths and natural skills and supports development. It is expected that early support is delivered by skilled and qualified multi-disciplinary teams that include deaf professionals (Gale et al., 2021), and that the intervention is sensitive and responsive to different family contexts, values, and cultures. Alongside this professional support, it is understood that caregivers also benefit from informal social support from family, community, and friends as well as voluntary organisations, clubs and groups (Rodrigo et al., 2007). Relationships among family, community and friends that are consistently responsive and sensitive, provide tangible emotional support (Zaidman-Zaid, 2007).

The evidence-base for these current early support protocols is orientated to studies in western contexts where early identification, intervention and reporting can be assumed. In Ghana, as in most LMICs, this infrastructure is not available to caregivers of deaf children. That
caregivers must ‘make do’ without this support is not acceptable and breaches the United Nations expectations of ECE for all (2015), the UNICEF convention on the Rights of The Child (2009) and United Nation Convention on the Rights of Persons with Disabilities (2007). Interviews with caregivers and education and hearing-health professionals in this study reveal the personal, social, and material resources in play, how they are deployed, and how they might be further exploited.

12.2 Encountering and overcoming difficulty

The period around the identification and confirmation of a child’s deafness is considered to be an overwhelming time for caregivers. Caregiver response to the confirmation of their child’s deafness is understood to be a significant factor in family adjustment, the building of caregiver-child relationship, and child outcomes (Kurtzer-White & Luterman, 2003). Research in this area tends to focus on the emotional responses of parents and their potential effect on child development, and the smooth interaction between child and caregiver (Meadow-Orlans et al, 2003; Pressman et al., 2000). Not all caregivers have negative emotional reactions to an identification of deafness. However, studies that reveal a potentially disruptive response highlight caregiver feelings of grief, guilt, and powerlessness (Kurtzer-White & Luterman, 2003) and the experience of denial, stress, and anxiety (Pipp-Siegel et al., 2002).

The caregivers in this study find the confirmation of the child’s deafness and the ensuing challenges of communication and unfamiliar decision-making to be stressful. They have not had the experience of prompt early diagnosis and intervention or early opportunities to gather unbiased and full information, or to meet deaf people. They thus find it difficult to make sense of their new situation and to make informed judgements. These difficulties echo the findings of other research into caregiver experience in LMICs (Oluanya et al., 2007 Opoku, 2020; Kabay et al., 2017; Rout & Khanna, 2012). Indeed, in these contexts, caregivers of children with disabilities in general experience higher levels of stress; they are reliant on their own resources, get little

8 Outcomes of interviews with education and hearing-health professionals are reported in Working paper 1.
early support and are easily discouraged (Bizzego et al., 2020). This experience is intensified where attitudes to disability are, in general, more negative. There is a greater experience of stigma and financial hardship associated (in the case of childhood deafness) with school fees, hearing technologies.

The narrative of overcoming the difficulties that pervade the caregiver interviews is associated in the western deaf education and deaf studies literature with a deficit and medical model of deafness (Ladd, 2005). In this context, this response to the experience of burden is a reality for caregivers. The understanding of deafness in social and linguistic, rather than medical and deficit terms, should be addressed at a societal level in order that caregiver expectations and responses are more informed.

None of the caregivers that we interviewed had met a deaf person either as a role model or as a supporting mentor. Research demonstrates that caregivers’ encounters with deaf adults develops parenting confidence (Hintermair, 2000) and improves the quality of deaf children’s early education (Gale, 2020). It is a recommendation of the Joint Committee on Infant Hearing that deaf adults should be members of early intervention teams (Moeller et al., 2013). However, the extent to which this is implemented beyond North America is limited (Gale et al., 2021), although there are some examples of good practice in South Africa (Störbeck & Pittman, 2008).

Support for caregivers in LMICs requires that existing stigmas around deafness are challenged and that the inclusion of deaf adults as role models and leaders in early intervention research and practice is facilitated.

12.3 Language and communication

The international early intervention guidelines stress the importance of parent-child interaction as one of the main predictors of children’s language outcomes (Moeller et al., 2013; Yoshinaga-Itano, 2020). The need to evaluate caregivers’ interaction skills is also a focus of research and there is a substantial body of work in the western literature (USA, Canada, Europe, Australia) that has looked at different aspects of parent child interaction, including the establishment of joint attention and engagement, the use of multimodal communication strategies and caregiver contingency or accommodation.
In Ghana, most caregivers of deaf children are hearing and do not know Ghanaian Sign Language (GSL). This is the case for the caregivers in this study who have had minimal exposure to GSL and are unable to access regular training outside of their locality. There is also no support infrastructure for early identification and support or family coaching, individual and group training, video-modelling; all frequent methods of intervention in the western contexts (Curtin et al., 2021). Caregivers thus develop their own strategies for communicating with their deaf child. They use gestures, spoken language, facial expression, writing and drawing, demonstrations and most have developed their own ‘home signs’. They get access to sign language teaching, although on an irregular basis once their child has started school. The amount and quality of linguistic input and communicative contingency and responsiveness, understood to be crucial in early interaction needs to be further understood in this context so that caregivers can be supported to build on the strategies that they have spontaneously developed.

In this context, caregiver communication choices are significantly influenced by negative societal attitudes to deafness and the lack of information about the communication possibilities of sign language. Access to deaf adult role models is not prioritised or facilitated and so caregivers have no experience of sign language competency and the potential of bilingualism. The need to develop spoken language dominates caregivers’ narratives about communication along with a belief that children can develop one or the other, but not both.

Much more work is needed in this area. Interaction studies of caregivers and deaf children in multilingual homes and communities in LMICs are scarce because of the lack of demographic information and early support programmes. While this situation continues, caregivers shoulder the burden and anxiety of communication difficulties that are a result of impoverished early support and limited societal awareness. Language and communication support for caregivers and their children needs to be informed by the international research but also embedded in context so that intervention work can focus on communication resources rather than the communication barriers that are already well documented (Opoku, 2020). This implies a focus on the full multimodal communicative repertoire of the child, the caregivers and the surrounding community and recognition of the linguistic (spoken and signed) and embodied communication strategies that are available and can be integrated to facilitate meaning making. Understanding
the communicative context of the home will also be important (Nutakor & Amfo, 2018). The use of coaching, training and video-modelling that is based on extending the skills that the caregivers already have, would then enhance established communication resources and improve parent confidence.

12.4 Caregivers as early educators

Caregivers are the immediate source of support for their child’s development, education and socialization. They are also crucial actors in facilitating educational participation and mobilizing external support. Caregivers’ own experience of education is likely to influence their agency, expectations, and efficacy in this role (Walker et al., 2011), alongside other situational factors including financial, geographical considerations and contextual influences (external advice, support, expectations).

Of the 12 caregivers that we interviewed, seven had a school-based education and three had gone on to higher education and training. One caregiver has no formal education. The three caregivers that had undertaken higher education had professional occupations (lab technician, senior nurse, pharmacist). Five of the caregivers had stable semi-professional employment (hairdresser, waitress, mechanic) and three relied on local street trading.9

In Ghana, the educational experiences for people differ between the rural and urban contexts. In rural areas, some communities do not have access to schools. So, as people in these communities strive to have formal education, the majority are educated up to basic school level. The problem with education of this nature in the rural settings is that it does not equip students with the requisite knowledge and skills in the usage of English for effective communication so most of the graduates prefer to communicate using their local languages. Only few people from such contexts are able to progress to senior high school level. In urban settings, since parents

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9 Street trading of produce, clothing and electronics on the streets is a source of income for people with low income and capital, especially women, in urban areas of Ghana (Akuoko et al. 2013).
are able to progress in their academic careers, they pick up jobs in the formal sector and are able to communicate in English in most of the time.

Education is valued by all caregivers in this study but not all of them feel equipped with the knowledge, skills or confidence to support their children’s learning. They have diverse experiences of education themselves ranging from no formal schooling to university-level qualifications and this diversity is reflected in the economic and employment status across the group. The caregivers with high levels of qualifications and professional employment are better positioned to engage with educational decision making and support and are more confident to ask questions and seek advice. Early education programming for deaf children in this context will need to take account of the skills and goals for development, learning, and life that caregivers bring (Keller et al., 2004; Nsamenang, 2008), and their diverse understandings of the value and purpose of early education (Kabay, 2017).

Caregivers are stressed by the education role they try to fulfil and the decisions that they have to make. Parents of deaf children experience more general parenting stress than parents of hearing children, especially in relation to language delays and child behaviour (Quittner et al., 2010). In this context, stress relates to questions of how to support development and learning at home, the communication challenges, the practical issues of school location, enrolment processes and the financial challenges of educational provision. Enrolment and access to education then brings further anxieties of separation as most children must leave home to attend a school for the deaf.

The development of an early support infrastructure around deaf children and their caregivers needs to be informed by, and respond to, these inhibiting anxieties. This level of support can usefully be nurtured within the communities around the caregivers (Opoku, et al., 2020) to alleviate the stress and burden on a day-to-day basis. Alongside this proximal support, steps need to be taken at an organizational/policy level to ensure that children are identified and enrolled in school early. Education and health practitioners have a role here with their resources to reach out to caregivers with encouragement and practical advice about how to get involved and further their child’s development and education at home.
Caregivers can also support each other. They demonstrate practical approaches to getting involved and supporting their child’s learning at home through the development of materials and through their engagement with the school and the teachers and at school. These strategies and the experience of decision-making about their child’s education could be usefully shared with other parents as part of an early intervention and support programme (Solomon et al., 2001). This is a core principle of all family-centred early intervention for deaf children (Henderson et al., 2014) and, as such needs to be re-examined in the context of different livelihoods and geographical and cultural dynamics of different societal contexts (Störbeck & Young, 2016).

13 Preliminary conclusions

This working paper describes our work in progress and offers a preliminary analysis of our conversations with caregivers with the intention of sharing our work and gathering feedback at an early stage. Through our preliminary analysis of caregiver narratives, we have tried to reveal the realities of what it means to be a caregiver of a deaf child in this context, and to gain an understanding of the factors that influence early care and support. These influences comprise a dynamic interconnection between the proximal responses, experiences and understandings that are part of the daily lives of families and societal awareness, knowledge, and infrastructure. Families do what they can with what they have and what they know, and they have communication, parenting and community resources that can be developed. However, there are external barriers relating to societal awareness, stigma and infrastructure that shape their experience of having a deaf child and constrain their access to support and information. Caregivers are thus caught in an eddy of anxiety, unfamiliarity, and inexperience with only partial (and sometimes incorrect) information about deafness, language, and communication.

A focus on the available resources and education at micro and macro levels in relation to families, communities, professionals, and policy makers would be a step forward in developing early support in this context. This needs to be done locally and based on in-depth contextual understanding. This work will extend understandings of the diverse contexts for early support beyond western experiences where prompt early diagnosis and intervention is carried out in line with best practice guidelines, and where caregivers are given early opportunities to gather
unbiased and full information and make informed choices. Such research cannot alter the available resources but can inform and provide an evidence-base for how these resources might be used and how to sharpen the focus on priorities. Research in this area can also provide evidence for, and strengthening, lobbying and advocacy work, and give authority to social awareness campaigns.
References


Kpobi, L., & Swartz, L. (2019). Ghanaian traditional and faith healers' explanatory models of


Rodrigo, M. J., Martín, J. C., Máiquez, M. L., & Rodríguez, G. (2007). Informal and formal supports


