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Caregiver Experiences: Caring for a Child with Cerebral Palsy Presenting with Speech Impairment at the University Teaching Hospital, Lusaka, Zambia

Mutinta Shaba[1], Micah Mutuna Simpamba[1]*, Hastings Shula[1], Brian Chanda Chiluba[1],

[1]Department of Physiotherapy, School of Health Sciences, the University of Zambia.

*Corresponding author: *micahm.simpamba@unza.zm*

Abstract

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Background: Many children with cerebral palsy present with disturbances in sensory, cognitive and motor development which subsequently affect the child's speech, language and communication development. Caregivers taking care of such children are heavily burdened and if not addressed such cumulative burden may in turn have influence on the quality of care for children with cerebral palsy. we set out to explore the experiences of caregivers of children with cerebral palsy who present with speech impairments and to identify which strategies they use to communicate with their children.
Methods: A qualitative phenomenological study was used. Data was collected using in-depth interviews from a purposively selected sample of 8 caregivers of children with cerebral palsy presenting with speech impairment at the University Teaching Hospital in Lusaka, Zambia.
Results: Three themes emerged from the data on caregivers' experiences caring for a child with speech impairments and one theme from data on communication strategies used by caregivers. The themes on caregiver experiences included impact of speech deficit; beliefs about speech impairment; and Lack of knowledge. The theme on communication strategies had three sub-themes namely understanding through the gaze; a different kind of sound; and trial and error.
Conclusion: This study has revealed that caregiver beliefs, lack of knowledge on availability of speech therapy and special education make it difficult for them to understand speech problems experienced by their children. Furthermore, the study also showed that caregivers devise their own strategies of communicating with their children despite the absence of speech and language therapy services.

Keywords: *Stress level, academic concerns, sources of stress, academic stress, stressor*

Introduction

Although caring for a child is a normal expectation of any parent who has a young child, this responsibility takes a different dimension when the child is diagnosed with cerebral palsy (CP). This is because cerebral palsy causes multiple impairments and functional limitations that require possible long term care (Huang, Kellett & St John, 2010). CP is one of the most common causes of neurological impairments in children worldwide and is associated with lifelong disability (Brannen & Heflinger 2006; Pakula, Braun & Yeargin-Allsopp 2009). The global prevalence of CP is estimated to be approximately 2 per 1000 live births globally and between 2 to 10 per 1000 live births in Southern Africa (Donald *et al,*. 2014; Oskoui *et al,*. 2013).

CP is an umbrella term that refers to non-progressive motor disorders that are due to damage to the fetal or infant brain. CP is accompanied by other multiple impairments including sensory, motor, speech, communication, eating and drinking limitations (Rosenbaum *et al*., 2007; Pakula *et al*., 2009). As a result, many children with CP experience life-long functional restrictions and consequently dependent on others for activities of daily living. Disturbances in sensory, cognitive and motor development can subsequently affect the child's speech, language and communication development (Pennington, 2008). Communication impairment is one of the most common comorbidities associated with CP, with prevalence ranging from 38% to 55 % (Zhang *et al,*. 2015). According to Rosenbaum et *al*. (2007), CP often affects the language centers of the brain that are responsible for control of speech. Bunning and colleagues (2014) also noted that children with communication impairments are more likely to be those with severe disabilities and hence may represent 2.2-3.8% of the WHO and World Bank (2011) prevalence estimates for children with severe disabilities. In addition, studies done on children with CP have found that children with speech and language impairments are likely to have spastic quadriplegia, cognitive impairments, severe motor deficits and grey matter injury on neuroimaging (Zhang *et al,* 2015; Nordberg *et al.,* 2013). In a study to describe the extent of speech problems in young people with CP, Cockerill and colleagues (2013), found that 63% had speech impairments and these were associated with severity of motor impairment, intellectual disability and epilepsy.

The consequences of speech and language problems can impact on the child's participation and activity within the home, community or school. Fauconnier *et al*. (2009) observed that children with communication difficulties would present with limited participation in social, educational, community life and a lower perceived quality of life compared to those without communication difficulties. In addition, poor speech intelligibility is associated with restricted communication between the child and the parent, and the presence of excessive drooling has a negative impact on the child's interaction with peers and on their self-esteem thus increasing their daily care needs (Pennington & McConachie 2001; & Van der Burg *et al.,* 2006).

Caring for a child with a disability places a substantial burden on the caregiver who assumes that responsibility. Raising a child with cerebral palsy is stressful for caregivers because it requires intensive physical engagement as well as emotional reaction to the child's condition (Krstic & Oros 2012). In a study that was done at the University Teaching Hospital in Lusaka, to determine experiences of caregivers of children with CP receiving out-patient Physiotherapy services, caregivers expressed being overwhelmed and need to make adjustments in terms of family and work, as well as the need for help in caring for the child with CP (Chiluba & Moyo, 2017).The impact of speech problems in the life of the child with CP and their family has far-reaching consequences and is associated with reduced participation in everyday activities, reduced quality of life in relationships with parents or caregivers, and problems with psychological adjustment (Dickson *et al.,* 2007; Fauconnier *et al.,* 2009).

The multiple health conditions associated with CP requires an interdisciplinary kind of management involving disciplines such as neurologist, physiotherapists, occupational therapists, ophthalmologists, pediatricians, psychologists, speech and language therapists, educators and many others (Trabacca *et al.,* 2016). Speech and Language Therapists address problems related to articulation, oral motor dysfunction and language skills (Aisen *et al.*, 2011). Some of the techniques used by speech and language therapists for children with motor speech impairments include vocal tract controlled breathing, phonation, nasal resonance articulation and intonation (Pennington, et al., 2010). In addition, individuals with complex communication difficulties can benefit from Augmentative and Alternative Communication (AAC) which can be used to supplement their speech (Muttiah *et al.,* 2016). There is evidence that speech and language therapy can have positive outcomes for children with communication impairments. In a modified time series intervention study conducted in England to test the potential effects of speech therapy techniques on older children with CP presenting with dysarthria, it was reported that therapy was associated with improved speech intelligibility (Pennington *et al.,* 2010). In another pretest post-test study design that was conducted in rural Kenya to investigate the impact associated with a home-based, caregiver implemented intervention using AAC, it was reported that there were statistically significant positive changes in caregiver perceptions of communication abilities of their children as well as improvements in the children's social activities (Bunning *et al.*, 2014).

Despite empirical evidence of the effectiveness of speech and language therapy, many people with communication problems in Low and Middle Income Countries (LMIC) do not have access to communication services due to lack of speech and language therapists in these countries (Bunning et al., 2014). According to the WHO report on disability (WHO, 2011), rehabilitation services in LMIC such as those in Sub-Saharan Africa are characterized with many challenges including lack of data on disability, lack of service providers and other resources, long waiting times, lack of awareness of the services and cultural barriers. In a review of speech and language therapists in four (4) countries across Sub-Saharan Africa, it was reported that the ratios of speech and language therapists to the population ranges between 1 therapist to 2-4 million people, compared to USA, UK and Australia which had 1 therapist to 2500-4700 people (Wylie *et al.,* 2013).

In Zambia, the proportion of 1 speech and language therapist to 2-4 million cannot be applied because the country has only one speech and language therapist employed in a public health institution with about 5 others who are in private practice. Rehabilitation services for children with CP comprise mainly of Physiotherapy, with a few health institutions providing orthotics services for assistive devices. Despite the lack of speech and language therapists in the country, the demand for their services is very high, especially among children with cerebral palsy who are the majority of patients receiving paediatric Physiotherapy services in the country. Records obtained from the 2018 UTH Physiotherapy paediatric out-patient clinic showed that approximately 60 children of different age groups were attended to every month. Among these, the majority were children with CP aged above two years and presented with different levels of speech impairments. Apparently, there are no speech and language therapists or Occupational therapists at UTH and all the children with CP presenting with different types of impairments are attended to by Physiotherapists. This poses great challenges for both the Physiotherapists and caregivers of these children. This study was therefore conducted to explore caregiver experiences and strategies they use to communicate with their children with CP who presented with speech impairments at UTH, paediatric out-patient Physiotherapy clinic.

Materials and Methods

A phenomenological qualitative study design was used to explore the caregivers' experiences with caring for children with CP who presented with speech impairments. The study setting was the paediatric out-patient physiotherapy clinic based at the University Teaching Hospital, in Lusaka. UTH is the largest tertiary level hospital in Zambia, located in the central area of the capital city Lusaka. A purposefully selected sample of 8 caregivers of children with CP presenting with speech impairments and aged above 2 years was used to collect data using in-depth interviews. Data saturation was used to determine the sample size and after interviewing the first 8 caregivers, there was no new data immerging from the in-depth interview.

Ethical approval and permission to conduct the study was obtained from the University of

Zambia School of Health Sciences Research Committee and UTH management respectively. The interviews were transcribed verbatim and data analysis was data using thematic analysis which involved classifying data systematically by means of coding to identify key factors or issues such as concepts, categories, themes and the relationship between them. The categories led to the development of patterns and themes within the data (Cresswell, 2003). The conformability of the research was enhanced by asking an independent reviewer (Supervisor) to analyze the raw data and compare the various categories and themes.

Results

Demographic characteristics

The age of the caregivers ranged between 20 and 43 years while that of the children ranged between 2 to 15 years of age. The gender for the children included three female and five males, while the types of CP consisted of spastic quadriplegia 4, with 2 spastic diplegia while the other 2 were athetoid. The other demographic characteristics for caregivers included marital status, educational level and employment status. 4 caregivers were married, 2 were single, 1 divorced and 1 widowed. Educational wise, 1 caregiver's education level was tertiary and the rest had not gone as far as tertiary education. On their employment status, only 1 caregiver was in formal employment with rest being unemployed.

Emerging themes

A total of four major themes emerged from the data analysis. These were as follows: *Impact of speech impairment, Beliefs about speech impairment, Lack of knowledge* and *Communication strategies*

Impact of speech impairment

The theme *impact of the speech impairment* was further categorized into three sub-themes namely; *Dependency on caregivers*; *Difficult to understand;* and *Stressful feeding*. Most participants revealed that speech deficits rendered the children dependent on their caregivers for most of their activities of daily living. They revealed that due to the children's speech impairments, they always had to be close to identify needs such as feeding and toileting which is sometimes emotionally draining on their part. Some participants further highlighted that they could not even go out to do other activities or look for jobs because they had to spend much of their time home caring for these children.

> "*I face a lot of challenges as you can see he can't talk or do anything…it's me to do everything for him*" (M3)

Regarding the sub-theme "*Difficulty to understand*", caregivers reported that sometimes it was difficult to understand what the child wanted and this resulted in misunderstanding the child which would subsequently result in the child resorting to crying for prolonged periods of time. When this happens, some caregivers stated that they would resort to trial and error hoping that they would eventually figure out why the child is crying. Some of the children would not even cry or give any gestures or signs but would just be quiet. In such circumstances, the caregiver would have to come up with mechanisms such as regularly checking on the child or responding to change in smell by checking if the child has soiled himself/herself

> *"Because he does not talk, it's difficult to know when he wants to go to the toilet, eat and or sleep…"* (M3)
>
> *"This one just starts crying then I will know that he wants something…whether sick or hungry he just starts crying, so it's difficult to know what he wants"* (M2)

With regards to the sub-theme *"stressful feeding",* most participants attributed the stress during feeding to inability of the child to express when he/she is full or whether the child liked the meal or not. Caregivers reported that feeding times were usually prolonged and characterized with bouts of chocking, coughing and sometimes seizures. Participants further noted that it was difficulty to let another person feed the child due to feeding and communication difficulties and this resulted in the same caregiver feeding the child. Some participants reported that they have to over-cook the food or make lighter consistency to make it easier for the child to eat the food with less difficulties.

> *“…This one no one is able to feed him home; they all don’t know how to handle him”* (M4)
>
> *“He cannot chew meat or fish so I have to mash it into a powdery form before I add it to the food he is going to eat”* (M2)

Beliefs about speech impairments

The caregivers’ beliefs about speech impairments were influenced by family and societal beliefs. Some participants revealed that the way other people in their families understood the causes and treatment for speech impairments in children influenced their understanding too. Family beliefs about speech impairments was mainly associated with witchcraft with treatment consisting of traditional medicine.

“Somebody did this to me, so if it came from the roots, I should go back to the roots.” (M5)
“We have been trying some traditional remedies …” (M2)

With regards to societal beliefs, most participants reported that the delayed speech in their children was perceived by the society as resulting from tongue ties. In this regard, some caregivers reported seeking solutions for tongue ties but never yielded results. Other participants noted that some people in the community would tell them that some children delay to speak so they should just wait and their child would talk with time.

> *“I was told by a friend that it’s a tongue tie”* (M1)
>
> *“People said that other children delay to start talking so we waited until the speech was not coming”* (M3)

Lack of knowledge

Participants expressed lack of awareness and understanding about speech therapy and special education for speech impaired children. Hence subthemes under lack of knowledge included limited awareness about speech therapy and limited knowledge about special education.
Most participants expressed lack of awareness about speech therapy and that most people in the communities are not aware of the existence of speech therapists in Zambia. They reported that if they knew that there were speech therapy services anywhere in the country, they would have taken their children for therapy.

> *“No, I don’t know that speech therapists exist in Zambia, I would take him there if I knew. At least I want him to start talking, even just pointing at things can do”* (M1)
>
> *“No, we don’t know anything, if we knew we would go there because we want him to be talking, at least if he talks”* (M3)

With regards to awareness about special education, some participants reported that they would want their children to start school but they were not aware about special education and the conditions for one to be eligible. One participant reported that when she took the child to the main stream school, she was upset when her child was rejected because of the speech problem. While some participants expressed the desire to enroll their children in school, some participants were not willing to take their children to school stating that the child is still young or the child cannot be in school because of the condition.

> *“Yes, I plan to start taking him to school as soon as possible; I just don’t know where to go and their procedure” (M4)*
>
> *“No plans yet because he can’t sit, he can’t talk, so we think his not fit for school” (M7)*

Communication strategies

Participants in this study revealed that for communication strategies to work, there was need for strong bond between the caregiver and the child. Sub-themes under communication strategies included Understanding through the gaze; a Different kind of sound; and Trial and error.

Despite the communication difficulties their children experienced, some participants revealed that they understood the meaning of feelings and desires of their children through gestures and certain expressions. For instance, certain gestures were used to express some activities of daily living, such as toileting and/or need to feed when hungry. One participant reported that when the child happily participates in play, then she would know he is fine, but when he keeps quiet despite the caregiver wanting to play with him, then she would know he is not okay. Other children's' gestural expressions reported by participants in this study included putting the tongue outside the mouth' and /or leaking lips while feeding as expressions to indicate that the child still wants to eat, while closing the mouth or turning the head away indicates child is full. Some participants reported that the child would use facial expressions such as smiling when they see/hear a familiar face or voice and frowning when not pleased with what they see or hear.

"*...when he wants to do poop he gives a certain gesture and I would know that he wants to poop"* (M5)

"*When he is not okay he is less active, he is too quiet, and does not participate when playing with him*" (M7)

"Any person when happy or sick you can tell by their facial expressions, like when happy he smiles and lifts his hands up, but when not fine looks sad"(M3)

Participants also reported that different kinds of sounds produced by their children helped them to understand the condition of their inner being. They revealed that some children would produce different kinds of sounds depending on their condition, such as if happy while playing there was a sound they made to symbolize happiness, and when not happy another different kind of sound was produced.

*"When he is happy he makes a certain sound while playing, and when not interested in an activity he makes a different sound and you have to stop otherwise he cries"(*M4)

"but sometimes makes some sounds specifically related to an activity, when his hungry there is a sound he makes, and when he wants to fall from the chair there is a sound he makes too so I know"(M1)

Communication strategies for participants whose children did not give any gestures or signs led to a sub-theme *"trial and error"*, which was characterized by trying a number of different methods and learning from their mistakes until they figure it out. Those whose children kept on crying revealed that they would keep on trying many different things and when the child stopped crying, then they would know that this was what the child wanted. For instance, one participant stated that for her when the child cried after feeding without any obvious reason, the first thing she thought of was 'toileting', but when it fails, she would try other things such as giving a toy.

"...she does not point, communication is a challenge, you have to do trial and error what you think is what she wants...You try several things until you find what she desires "(M2)

Discussion

The demographic characteristics of caregivers in this study showed that the age range was between 20 to 43 years of age, majority were unemployed and did not reach tertiary level education while half of them were married. This being a qualitative study with a smaller sample size, the demographic characteristics may not be discussed in comparison with other studies that used larger populations. However, it is important to note that these characteristics are similar to other studies that have been done among caregivers of children with CP in other populations. Furthermore, a study which used the same population but with a much bigger sample size (25) reported the age range of between 26 years to 50 years (Chiluba & Moyo, 2017). The employment status and level of education for caregivers in this study are similar to other findings from other studies in the region. A study that was done in Kalifi, Kenya showed similar findings on mothers of children with CP who had poor education and were not in employment (Gona, Mung'ala-Odera, Newton & Hartley, 2011). The employment status and level of education represents the socio-economic status and CP, like any other disability is associated with low socio-economic status (WHO/World Bank 2015; Resch *et al.,* 2010).

The participants described the impact of the child's speech impairment had in terms of dependency on caregivers, difficult to understand and stressful feeding. Generally, studies that have been done on caregivers caring for children with CP have reported many different challenging experiences including emotional stress, lack of information, financial and physical strain, impact on caregiver health and inconveniencing/tiresome (Chiluba & Moyo, 2017; Gona et al., 2010; Murphy et al., 2007). The dependency on caregivers for most of the activities of daily living is expected for many children with CP presenting with speech impairments as literature show that speech impairments are significantly associated with severity of CP with regards to Gross Motor Functional Classification System (GMFCS) (Delacy *et al.,* 2016; Zhang *et al.,* 2015; Bunning *et al.,* 2014; Nordberg *et al.,* 2013). In a cohort study that was conducted in Australia to describe the profile of children with CP aged 5 years, it was reported that the increasing proportion of speech impairment and non-verbal status was seen with increasing GMFCS level (Delacy *et al.,* 2016). Problems associated with difficulties understanding the child with speech impairments which were reported in this study have been reported in other similar. A study that was done to describe the perceptions of parents and professionals about the quality of life of children with speech and language impairments, reported that communication break down between the child and family was identified as a factor that contributed to relationship difficulties between the child and family as it would often result into frustrations for both parties (Markham & Dean, 2006). The stress associated with feeding the child with CP has been reported in other studies including the study by Adams and colleagues (2012) who reported that caregiver frustration during mealtimes was due to length of meal times, need to modify food and prepare separate meals, among others. These challenges would usually result in caregivers resorting to practices such as reducing the frequency of feeding the child which would subsequently increase the risk of malnutrition for the child as was reported in another study that was done in Lusaka, at the University Teaching Hospital (Simpamba, Swart & Mweshi, 2020).

Family and societal beliefs are important in influencing caregiver response towards the child's disability as reported by some participants in this study who were advised by other people not to be bothered about the child's speech problems because some children have delayed speech. This is consistent with Norbury and Sparks (2013), who observed that local beliefs about the child's development may be highly influential in determining whether the child would get clinical attention or not. Some of the caregivers in this study were influenced by their families to believe that the child's disability including speech impairment was due to witchcraft and hence resorted to seeking traditional remedies. Other studies in the region have also reported similar findings (Gona et al., 2015; Zuurmond *et al.,* 2015; Markham & Dean, 2006). Lack of knowledge about the child's impairments and need for special education was another major theme that emerged from this study. It is obvious that the lack of caregiver awareness and understanding of special education services for their children could be due to lack of knowledge about the child's condition. This could also be true with regards to speech therapy services if they are available, but in this case, the services are not actually available in the country. Interventions focusing on training caregivers and empowering them with knowledge have been found to influence early academic and communication skills development for the child due to early intervention services (Malar, Sreedevi & Suresh, 2013). The positive attitude expressed by most participants towards speech therapy and special education during interviews is evidence that if they were empowered with knowledge and services were available, they would actually take their children to these services.

Communication strategies used by caregivers resulted in three themes namely understanding through the gaze, different kind of sound and trial and error. These experiences are consistent with studies done in other countries which lack rehabilitation professional such as speech and language therapists. In a study that was done to understand how Ugandan families cope with their disabled children, it was reported that parents of children with communication problems would devise signs to communicate with their children despite the process being tedious and sometimes would result in communication break-down (Hartley et al., 2005). Caregivers in this study expressed having developed strong bonds with their children which in turn resulted in developing mutual communication strategies. This is consistent with Baltor and colleagues (2014) who observed in their study that the conviviality between the children and caregivers enabled the caregivers to know and understand their children's reactions and expressions as well as comprehending the way of gazing and realizing what the children were feeling.

Conclusion

Revelations of caregivers experiences from this study for children with CP presenting with speech impairments, is that there is at most a lot of beliefs around why the child has speech difficulties and sometimes a lack of knowledge on the availability and associability to services such as speech therapy and special education would make it even difficult for most caregivers to understand speech problems experienced by their child. Furthermore, the study also showed that despite the challenges and absence of speech therapists, caregivers devise their own strategies of communicating with their children.

Declarations

Acknowledgement

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Conflicts of Interest

The authors declare no conflict of interest.

Author Contribution

All authors conceptualized the study. MMS, FMS, BCC and HS wrote the manuscript. All authors read through the final manuscript and approved the final copy before submission for publication.

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