

Why new parents of deaf children also have to learn to cope emotionally with the knowledge that their baby is deaf?

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Most parents of children who are deaf in Kenya find it difficult to parent these children since in most cases the parents are hearing and have lived to appreciate hearing as the norm. When this norm is turned upside down one day when they discover their child or children are deaf, their world comes crumbling down. In most cases these parents may have no prior contact with deafness of deaf children. Thus the realization that their child(ren) is deaf comes as a shock. Nine out of every 10 deaf children are born by hearing parents and only one in every 10 deaf children is born of deaf parents. This statistic contributes a lot to the shock and disbelief that besets members of a family that get a deaf child. It gets more complicate for first time mothers since the identification of hearing loss in their child is only the first stage, they also have to learn how to emotionally cope with the fact that they have a deaf baby. The onset of deafness is something that

also confuses parents since early identification is not done in Kenya in most cases. It is not until they try to communicate to the child using speech and realize there is no response that parents start to suspect there is something wrong with their child. This paper focuses on the challenges that parents of the deaf face on discovering that they have a deaf child and especially so for first time mothers. Early identification is advocated for and compulsory acquisition of Sign language by hearing parents of deaf children is encouraged since the two would act as a guarantee for the acquisition of Sign Language by most deaf children naturally. As compared to the current situation where majority of deaf children go past the “critical stage” in language acquisition without a language; this of course has an effect on both the parents and the children themselves as Seligman points out, “A disability in one family member affects the entire system and in turn affects the disabled person”. We also examine the effects of deafness on the deaf child.

Key Words: *Parents of deaf children; Coping emotionally; Kenyan sign language; Deafness; Early intervention; Acceptance and integration*

INTRODUCTION

The realization that a child is deaf causes stress in families who have had little contact with deaf persons and known about the implications of deafness. In addition to coping with the shock of the initial diagnosis, families must acquire understanding of a substantial and complex body of knowledge Terri Feher-Prout (1996)

LITERATURE REVIEW

Mary was delighted when the doctor declared that it was a baby boy. Nine months down the line and four pregnancies later finally; a boy. It was such a relief for her at least her in laws will not be on her case anymore [1]. Ever since she got married and since her first child and the ones after happened to be girls, pressure was brought to bear upon her to give the clan a boy. In the culture she was married into – the Giriama found along the Kenyan coast, apparently boy were valued more than girls. “A boy child is perceived to be the one in a better position to withstand harsh conditions as compared to a girl, therefore, is allocated chores that require him to be physically challenged, like staying out in the bush for days tracking down cattle with the wild being his only source of food and comfort” [2]. The boy child is viewed as responsible for security of the family especially in the absence of the father. This explains why the boy child is celebrated more than the girl child when born in this and many African cultures.

Thus when the news was announced that Mary finally had a baby boy five ululations rent the air as is normal in this culture to celebrate the birth of a boy and usually four ululations for a girl. There was a party the day the child who would eventually be named Charo was brought home. Little did Mary know she was about to begin a life of misery and suffering. Charo grew up a very healthy child. Being the fifth child the mother was well aware of how to bring up children. In the first six months Charo went through the stages all children go through – 0-3 months, he produced birth

cries, was able to laugh and smile, like any other child his age he would cry when in discomfort, when hungry, in pain and was able to maintain eye contact. During this stage, cooing and crying is a way of practicing their vocal cords. 4-6 months he went through the babbling and vocal play stages. All these activities were assurance enough for Charo’s mother that all was well [3].

This basically means it takes longer for a parent of a deaf child to realize that their child is deaf since to a large extent most are not prepared to raise Children with hearing lose. The length of time it takes to discover the child’s hearing lose has its positive and negative side as Cardona asserts [4].

“The positive aspect of this longer time frame is that the parents had time to bond with their infant; the negative is that this is crucial language learning time and the child with a hearing loss is already put behind their peers” [5].

The other fundamental issue in this regard is how the news of the child’s hearing lose diagnosis was eventually imparted to the hearing parents. Thus health care professionals need to be sensitive when breaking news of this nature. This is also emphasized by Northern and Downs [6] when they talk of the importance of healthcare professionals and audiologists being sensitive to the needs and feelings of the family and the child with hearing loss.

Back to Charo’s story; one year down the line things changed drastically. One day Charo’s mother tried to draw his attention while he was facing the opposite direction and there was no response. At first the mother thought he was just concentrating on what he was doing. “Charo!” “Charo!” The mother shouted. No response. She shouted over and over, no response. She panicked and ran very first to where her child was and picked him up. He seemed okay. Maybe he was just being rude or something. She let it pass. From there hence forth however, she actually noticed something strange. Any time she tried to communicate with him she had to make eye contact

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otherwise there was no response. She got worried and decided to take Charo to hospital. After several tests the verdict – your child is deaf!! Those four words sounded like the end of the world for Charo’s mother.

The shock

Grief -shock, anger and denial set in [5]. This the story of many hearing parents of deaf children. "Oh, yes, hearing parents go through the stages of grief-shock, anger, denial and all that.

Hearing families with no experience of deafness experience grief and shock as reaction to the diagnosis of deafness. That was what Charo’s Mother was going through upon receiving the news. The realization that a child is deaf causes stress in families who have had little contact with deaf persons and thus know little about the implications of deafness. In addition to coping with the shock of the initial diagnosis, families must acquire an understanding of a substantial and complex body of knowledge. Parents are often swamped with information on amplification devices, sign language, educational methods, school placements, and legal issues, all of which demand comprehension to assure appropriate critical decisions about the deaf child's future [7]. This is of course in most cases regardless to the degree or level of hearing loss.

Hearing parents of deaf children after the initial shock turn on themselves; they become angry at themselves imagining that they may have done something wrong during the pregnancy. As Alberg, J shows: “I know this happened I know this happened because I sanded the floors while my wife was pregnant.” They start feeling guilty and start blaming themselves and sometimes blame others too. This anger and guilt is as a result denial – why us? This can’t be happening etc. Like all people in denial they may seek to blame others, witchcraft, or family lineage with the spouses blaming each other’s lineage. They may resort to second opinions from doctors, visits to witch doctors etc. While all this is happening Charo meanwhile is the one on the line. What most parents of the deaf don’t seem to understand is that deafness is just but an impairment of hearing. An impairment being a loss or abnormality of bodily function which need not lead to a disability but one can understand why most parents of deaf children in Kenya view deafness as a disability since there is little to show in terms of role models and availability of a conducive environment that would go to dispel their fears. A conducive environment that would reassure Charo’s mother and many mothers and parents like her that it’s ok to have a child who is deaf because this is how, he/she will progress through life to her fullest potential. In the absence of these assurances, the parents are justified to go into denial. It is an emotionally draining experience.

But despite all the emotional experiences parents go through, it is important to note as Luterman [8] notes: “The key to a successful integration of hearing loss into a family is the degree to which parents are able to integrate hearing loss into their lives.” The birth of a child with a hearing loss into a hearing family can have a drastic impact on the family as well as on the development of the young child.

Challenges of deafness

In Kenya being deaf presents major challenges-deaf people are unable to perform day to day activities with ease thus they suffer activity and participation restriction all of which impact adversely on their social, economic and environmental participation. When deafness, an impairment of hearing interacts with an environment that is not conducive then it disables whoever possesses it. Another factor that discourages hearing parents of deaf children is the fact that their children cannot communicate “normally” like all the children in the neighbourhood who are talking. Only their child is not. Again parents fail to understand that deaf children have a unique communication need. That as long as their child has been diagnosed deaf his or her only problem is one of communication.

The reason why deaf children normally have a unique communication need is because as pointed out earlier stated 90% of deaf children are born and bred by hearing parents in an environment that does not expose them to sign language acquisition. However, only 10% of deaf children have the

“privilege” of having deaf parents and therefore growing up in an environment that enables them to learn Sign language (SL) naturally [9]. This means that majority of deaf children in Kenya do not learn Kenyan Sign Language (KSL) naturally as their first language. This has immense negative social impact since the language (spoken) used by the majority around them is inaccessible [10].

This inaccessibility of the majority language and the neglect of their natural language by their parents and those around them make life difficult for them. Imagine Charo by age five will not have learnt a language of communication. Being deaf he will live a life of isolation, be subject of ridicule by those around him. How frustrating can this be to both Charo and his parents? Though he may develop home signs that he can use for basic communication within the home, this is not language perse. What this means is that most deaf children normally go past the critical period in language acquisition which represents the development period that provides optimum opportunity for the acquisition of language, normally from birth to until the onset of puberty [11].

How does one survive without language? It’s a tale of frustration for both the deaf and the parents. Because most parents are so frustrated by not knowing what to do with their child, they resort to sending them to schools for the deaf early. The schools somewhat serve as a savior to most deaf children. In school the 90% of deaf children meet the 10% who are native signers and they assist in the KSL acquisition. Within a short period of time therefore, the 90% of deaf children are able to acquire a native speaker’s competence in KSL as long as the school environment is conducive. While the deaf child learns KSL and is able to communicate with other deaf children, the parents are left behind wallowing in self-pity. Charo would learn how to move on. But how about the parents? How do they parent their children without a common language?

The story of Charo is one that calls for early intervention which includes any intervention measures applied in a child’s life during the period ranging from birth to the time the child joins school for the purpose of arresting a certain adverse condition [12].

The early interventionist strategies are lent credence by the fact that most hearing parents with deaf children find it very hard to cope with the situation and thus, as mentioned earlier, they more or less “dump” their children in schools for the deaf. There is lack of proper communication at home normally since most homes offer a predominantly speaking environment for the deaf child. Early intervention here therefore means that parents need to take control of their deaf children’s life by realizing that once the doctor is through with diagnosis of deafness it stops being medical and becomes an issue of communication. They therefore need to go out of their way to learn KSL. As has happened in developed countries such as Sweden, there should be early intervention programmes which ensure that once a child is identified as deaf, the parents are mandated and given an opportunity to learn SL as early as possible [13]. In principle, such a programme should ensure that parents of deaf children are given mandatory leave to learn KSL early enough to give the child an opportunity to grow up in a signing environment [14]. This would ensure that the child grows in a conducive environment.

CONCLUSION

What parents of the deaf go through is more or less what people feel when they go into a new culture for the first time. At first the excitement of having a baby and in the case of Mary a baby boy for the first time is equivalent to the honeymoon stage or the initial euphoria stage characterized by curiosity, fascination and excitement at this stage, even if parents notice something different, they tend to neglect differences and reinforce similarities. Parents are excited, positive and highly optimistic about the future.

When Mary suspects that there is something wrong with her baby and the doctors confirm he is deaf, denial sets in. This is the frustration or crisis period. Here the parents come face to face with the reality of their child’s hearing loss and the stark reality that their child is different. This is equivalent to the culture shock stage. When people are immersed in a new

culture, "culture shock" is a typical response. They should anticipate that they will probably feel "bewildered and disoriented at times.

This happens to parents of deaf children at the initial stage of the discovery. They go into culture shock and sometimes withdrawal is inevitable especially when they come face to face with the reality of the fact that their child is different. They might even dislike the child since its behavior is unusual and unpredictable. The parents have this feeling of powerlessness, anger, can be highly irritable and as a defense mechanism can start developing stereotypes about people who are deaf. Eventually however, parents begin to adjust and slowly accept the situation and look for ways to cope. Thus home signs may be used with the child. The most important thing that is required here is acceptance and ability to adjust for the parents. Acceptance of the fact their child may not be able to access speech forever but that as a hearing person they have the capacity to learn the language of the deaf – KSL. This attitude change leading to acceptance and adjustment would require a flexible, tolerant person. One who is motivated to do all it takes for their deaf child. Learning KSL so as to properly parent the child, be able to follow up with his/her school work, provide a conducive environment in the home by encouraging members of the family to also learn KSL. This then will make the deaf child feel loved and always happy to be home.

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