**EXPERIENCES OF HEARING PARENTS REGARDING THEIR CHILD’S HEARING LOSS**

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**ABSRACT**

*An estimated 90% of children with a hearing loss are born to hearing parents. Most parents are unprepared for the diagnosis, leaving them shocked, confused, sad and bewildered. This article reports on a study aimed at exploring and describing the experiences of hearing parents regarding their child’s hearing loss. The study applied a qualitative methodology with a phenomenological design. Purposive sampling was implemented and data were collected by means of unstructured in-depth interviews. Data were analysed using thematic analysis. Ethical considerations were adhered to. The main findings of the study indicated that hearing parents experience a myriad of emotions when their child is diagnosed with a hearing loss. This study advocates for various stakeholders in the helping profession to collaborate in the best interest of the hearing parent and deaf child. Furthermore these findings serve as guidelines for professionals working with these families.*

**KEYWORDS:** Hearing parents, diagnosis, children with hearing loss

**INTRODUCTION**

It is estimated that 700 million people worldwide suffer from hearing loss (Toriello and Smith, 2013) and more than 900 million people worldwide will suffer from hearing loss by 2025 as estimated by the British MRC Institute of Hearing Research. The latest figures from the World Health Organisation (WHO, 2015) suggest that some 360 million people have hearing loss, and that roughly 32 million of them are children. In South Africa, it is estimated that 3.6% of the population were classified with a hearing loss (General Household Survey, 2015) however this number did not take into account the number of children under the age of five years old. A study conducted by Swanepoel, Storbeck and Friedlander (2009) estimated that three in every 1000 babies born in the private sector may be diagnosed with a hearing loss.

As the number of people and children with hearing loss increases, there is evidence to suggests that 90 to 96% of children born with a hearing loss are born to hearing parents (Kushalnagar, Mathur, Moreland, Napoli, Osterling, Padden and Rathmann, 2010; Krywko, 2012; Estabrooks, 2012; Lederberg, Schick and Spencer, 2013; Fritzpatrick, Stevens, Garritty and Moher, 2013). Previous research has shown that parents experience shock, denial and sadness when they discover their child has a hearing loss (Frank-Briggs, 2012; Gilliver, Ching and Sjahaham, 2013) and that parenting a child with hearing loss can be challenging and stressful (Quittner, Barker, Cruz, Snell, Grimley and Botteri 2010; Plotkin, Brice and Reesman; 2013). Although parents play a specific role in the development of their children (Integrated National Disability Strategy, 2007:5), their own journey of parenting a child with a disability also needs to be understood. Gilliver et al. (2013) concludes that parent’s recollections of their experiences with raising a child with hearing loss at a young age, indicates a significant grief related response and parents faced various emotional and physical challengers when raising a child with a hearing loss.

This article focuses on the experiences of hearing parents regarding the diagnosis of their child’s with hearing loss. Further attention is given to their emotional journey, and challengers regarding decision making, communication and discipline. It is envisioned that the knowledge and insights gained in this study will contribute to the helping professions in improving service delivery to hearing parents and their child with a hearing loss.

**PROBLEM FORMULATION**

When hearing parents are faced with the diagnosis of their child’s hearing loss, it often results in a significant life-changing event for both the parent and the child (Frank-Briggs, 2012; WHO, 2015). Their response to the diagnosis often shows significant similarities to the theory of grief as pioneered by Kubler-Ross (1969). In the event of death, a very traumatic experience, there is an expectant that grief will be resolved. Disability however, resolves in continuous life- long emotions for those that live with people who are disabled (Doğan, 2010). Similarly Costantino (2010) states that the diagnosis could bring about a different type of death, the death of important cognitive and physical functioning in a child. At the time of the diagnosis, hearing parents are often bombarded with information about education and language choices, but not provided with opportunities to express their grief, loss and challenges Although there has been extensive literature on the impact of hearing loss on parents and family (Jackson and Turnball, 2004; Krywko, 2012; Frank-Briggs, 2012; Zuidman-Zait, Most, Tarrasch, Haddad-Eid and Brand, 2016) this study specifically wanted to explore and describe the journey of hearing parents experiences regarding their child’s hearing loss.

**RESEARCH METHODOLOGY**

The study was located within a qualitative research approach as it sought to answer the research question by gathering descriptive data about a social phenomenon that was grounded in the lived experiences of parents whose children was diagnosed with hearing loss (Tracy, 2012; Marshall and Rossman, 2011). According to Creswell (2009), a qualitative researcher builds a holistic picture by analysing words, reports detailed views of the interviewee and conducts the study in a natural setting.

The strategy of design best suited for this study as argued by Titchen and Hobson (2005) and Finlay (2011) was phenomenology as it studied a lived world, human phenomena in everyday social contexts occurring from the perspective of those who experience them and doing justice to their everyday experience. Grbich (2012:92) adds that phenomenology is an attempt to understand the “hidden meanings” and the “essence of an experience” together with the participants and how they make sense of these experiences. The study therefore allowed for a story to be told that few know about, creating an opportunity to hear from those affected by a certain phenomenon (Tracy, 2012), namely the experiences of hearing parents regarding their child’s hearing loss.

The population for the study, was hearing parents with children who had a hearing loss between the ages 0 – 10 years. To gain access to the participants, the researcher approached a local organisation of the deaf, namely the Deaf Community of Cape Town. Volunteer and snowball sampling (Castillo 2009) was used to obtain a sample of 11 hearing parents. The number of participants as pointed out by Pitney and Parker (2009), Kumar (2011) was determined by data saturation.

Data was gathered by means of individual un-structured interviews. These in-depth interviews as explained by Creswell (2007) and Klenke (2008) provided the researchers with an opportunity of going beyond the surface of experiences, probing into the details of the participants’ emotions and the meaning that they attached to their child’s hearing loss. Thematic data analysis was conducted. The thematic analysis identified, analysed and reported patterns (themes) within the data whereby it looked for emerging themes, relationships and dynamics within the findings (Carey, 2012; Mills, Durepos and Weibe, 2010). The trustworthiness of qualitative data, was identified through truth value, applicability, dependability/consistency, and neutrality (Krefting, 1991). The study had to reflect the accuracy of information that was provided by participants and these accounts needed to be trusted and be seen as credible (Creswell, Plano and Clark, 2011). Ethical considerations for the research included autonomy, confidentiality, and anonymity by using pseudonyms and ensuring no harm to participants as well as debriefing (Hess-Biber, and Leavy, 2011; Denzin and Lincoln, 2003 and Rossman and Rallis, 2011). Participants provided written consent to participate in the study and were informed of their right to withdraw from the research. Permission from UWC Ethics Committee as well as the Deaf Community of Cape Town was obtained before the commencement of the research.

**DEMOGRAPHICS OF THE PARTICIPANTS**

**Table 1 Biographical details of the participants**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Gender:** | **Marital/ Status** | **Race** | **Employed /** | **Age of Deaf Child** | **Position of deaf child in family** | **Age of onset** | **Type of hearing loss** | **Cause of Deafness** |
| Female | Single | C | Yes | 10 | Only child | Unsure | Hard of hearing | Unknown |
| Female | Single | C | Yes | 6 | Eldest of two | 1 year | Hard of hearing | Unknown |
| Female | Married | C | Yes | 10 | Youngest of two | Birth | Profoundly deaf | Rubella |
| Female | Married | C | No | 9 | Eldest of two | Unsure | Hard of hearing | Unknown |
| Male | Married | C | Yes | 9 | Eldest of two | Unsure | Hard of hearing | Unknown |
| Female | Married | W | Yes | 10 | Youngest of two | Birth | Hard of hearing | Ear infection |
| Female | Separated | B | Yes | 7 | Eldest of two | Unsure | Hard of hearing | Unknown |
| Female | Married | C | Yes | 10 | Eldest of two | Unsure | Hard of hearing | Unknown |
| Female | Married | C | Yes | 8 | Youngest of three | Unsure | Profoundly deaf | Unknown |
| Male | Married | C | Yes | 10 | Youngest of three | Birth | Profoundly deaf | Unknown |
| Male | Married | C | Yes | 10 | Youngest of two | 3 years | Hard of hearing | Meningitis |

**Demographic details**

The participants in the study constituted a heterogeneous group in terms of age, household, relationships, educational and socio-economic profiles. Eight hearing mothers and only three fathers of a child with hearing loss were interviewed.

**RESEARCH FINDINGS AND DISCUSSIONS**

The findings of the study that emerged from the qualitative data was contrasted and compared with other existing studies and literature around the topic. The four central themes that emerged from the data, including verbatim quotations of the hearing parents’ are discussed under the following headings:

**Theme 1: Shared initial emotional reactions during time of diagnosis**

Existing literature on disability alluded to parents’ initial emotional reactions to the news of a diagnosis of a disabled child as that of shock, denial, guilt, blame, fear, depression, anger, frustration, acceptance and emotional trauma (Flasher and Fogle, 2003, Kandel and Merrick, 2003, Ross and Deverell, 2004, Shovhov, 2004 , Seligman and Darling, 2007, Worden 2011, Abdelmoktader and Abd Elhamed, 2012).

Data pertaining to this study echoed the findings of the aforementioned authors as participants described their shock and confusion regarding the diagnosis of their child’s hearing loss by means of the following: *“…I was like, what? ...is this man serious? This was like a blow for me…”, “I was shocked; I just sat there for a little, confused…”,“… I was thinking, oh my word, my world is going to end, what’s going to happen to this child?”, “I was confused. I thought deaf people are dumb, they can’t read, they can’t write, can’t speak”.* These responses alluded to the notion that hearing parents are not prepared for such a diagnosis and that they were initially shattered. Dare and O’Donovan (2003:240) suggest that parents should not only be given time to understand the diagnosis, as they will inevitably go through different emotional stages, but also need to grieve for their apparent “lost baby” as they feel overwhelmed when their child is diagnosed with a hearing loss (Dehkordi, Kakojoibari and Yektakhah, 2011).

The initial shock was followed by denial and disbelief as participants struggled to accept and believe the diagnosis and lamented as follows: *“I didn’t want to believe it…”, “We were in complete denial…. How can it happen to our child? How can our child be deaf?”,* “*...and found that she was deaf, I couldn’t believe it”, “I said nonsence”.* While Brown (2012) and Northen and Downs (2002) confirm that denial or disbelief by parents is a typical reaction that will follow shock, Dare and O’ Donovan (2003) reckons that denying the child’s permanent disability, often serves as a self-protecting mechanism for parents. Putz (2012) again, regards it as hearing parents coping mechanism that is neatly packaged when they are not ready to deal with their child’s hearing loss.

Subsequently, most of the participants went for second opinions afterwards, even those who suspected that something was wrong with their child at the time of the diagnosis, secretly hoping that everything would be fine. Nielsen (2008) allude to the fact that denying the existence of hearing loss will often result in parents visiting various healthcare professionals in search of a better diagnosis or even a cure for the hearing loss While parents are still attempting to change their reality, Ross, Storbeck and Wemmer (2004) and Wall (2003) believe this is when hearing parents begin to move into a state of denial. Responses from participants were as follows: “…*we sought a second opinion”.” I didn’t want to believe the diagnosis and I for sure wanted a second opinion…”*

In addition to “shopping around” for other diagnosis, some participants tried to dissect the diagnosis in order to find some meaning. They asked “why” and “how” questions. These questions warranted their concern as they did not know what to do or what to expect and therefore searched for answers. Dare and O’Donovan (2002:17) view this process as an important stage in the denial phase as it serves as an attempt to process and understand the diagnosis of their child’s hearing loss. Cole and Flexer (2015), therefore emphasizes the importance for parents to understand the etiology of the child’s hearing loss, as well as the causes.

Furthermore, the participants also reflected on their sadness and grief when they learned about their child’s hearing loss and lamented as follows: *“I cried a lot…… I cried almost every time……”, “I was so sad, I was heartbroken, I cried for months…”, “I never expected my child to be deaf. I was oooo so heart sore”, “I remember going to the bathroom at times and just sitting there and crying”, “Ooo I was sad. I cried for months because when she was born there was nothing wrong.”* The participant’s sadness was synonymous with chronic sorrow and ongoing grief about their shattered dreams for themselves and the child with hearing loss.

Sadness also seems to be a recurring emotion that was revisited each time a child approached a developmental milestone (Flasher and Fogle, 2003). Ross et al. (2004:156) however, warns that parents who are unable to move beyond the stage of sadness can become depressed and those experiencing chronic sorrow will be in need of professional assistance over time.

**Theme 2: Specific behavioural and emotional reactions following the diagnosis of the child with hearing loss**

Hearing parents also reported specific emotional-behavioural responses of anger, guilt and blame after their child was diagnosed with hearing loss. Expressions such as“*I was very angry….. I was still very young and wanted to go on with my life”,* “*I feel as if I am trapped”*, “*I am at home all day…, I can’t work and that makes me cross as we have many problems”…* portray their anger as a result of having to deal with many issues pertaining to their child’s disability*.*

Ricci and Kyle (2009) confirm the aforementioned parent’s anger about the loss of their normal child, lost opportunities, lost ambitions and even feeling bitter and cheated by life and fate for giving them a disabled child. Dowling, Nicoll and Thomas (2013:46) view anger as one of man’s strongest emotions, providing them with protection from emotional trauma and often arises when one feels anxious, helpless and overwhelmed by a particular situation, such as the diagnosis of a disabled child. Kriegsman and Palmer (2013) also assert that anger is a normal coping mechanism after being confronted with major loss and trauma, and plead that they should be given the opportunity to vent their feelings about their child’s disability. Similarly Blass (2012) warns that parents often feel angry towards the disabled child because of all the time, effort, energy and attention they require and that especially teenage and single mothers will feel trapped if they lack support from family members (Dare and O’Donovan 2003).

Hearing parents recalled significant reactions of guilt and blameonce they learned of their child’s diagnosis. Keeping in mind that the birth of a disabled child introduces a severe strain into the family, parents blamed each other leading to accusations and arguments between them. Nielsen (2008) refers to guilt as the underlying feeling of anger and a normal part of the grieving process. Interesting enough, self-blame was evident among the hearing mothers who reported how they questioned themselves whether they had done something wrong during the course of the pregnancy, why and how it happened, blamed themselves and even“*felt like a failure*.” Frank- Briggs (2012) and Dowling et al. (2013) are in agreement that mothers in particular often feel a sense of unfairness and might go over their pregnancy to figure out what they may have done to cause their child’s hearing loss.

In addition, one of the participants blamed her daughter’s biological father by means of the following statement:*“I blamed him. When I told him I was pregnant, he told me to do away with the baby [abortion]. That curse is on the child, all those words, all those negative things put a curse on the child”.*

Often hearing parents become stuck at the time of the diagnosis, asserting blame and often tend to struggle to get beyond this point. Similarly, one of the participants asked God“*if he was punishing her now for falling pregnant at such a young age*.”, thus projecting her blame for the child’s hearing loss on God. Similarly, Blass (2012:326) same parents are apportioning anger to God for “visiting this injustice upon them and their baby”. Based on some religious beliefs, parents may even think that the birth of their disabled child is a “curse” and a “retribution” by God for the sins they have committed (Alur and Bach, 2012:164).

Anger and blame was also proportioned towards health care professionals such as the negative manner in which the diagnosis was relayed to them. One of the participants reflected that *he [the doctor] was cold by showing his back to us, ... he wasn’t very friendly. It was like ‘I’m just doing my job here, just accept your child is deaf”.* The participants thereforeasserted that if the diagnosis had been presented in a gentler, more positive manner, it would have been easier resulted for them.

Martin and Clark (2006) and Knight (2007) therefore stress the fact that healthcare professionals seem to be unaware of their great responsibility in presenting diagnostic results and that their matter-of-fact attitude in conveying the diagnosis can have an enormous effect on hearing parents' emotions. Although there is no way to cushion the shock, a sympathetic attitude and an understanding attitude towards parents' feelings could assist in their coping better (Northern and Downs, 2002). Similarly the findings of this study also pointed to anger and blame projected by the participants onto healthcare professionals who dismissed parents’ concerns about a possible hearing loss in their child, thus resulting in a prolonged diagnosis. One of the participants reflected on her frustration and anger when her own observations of her baby’s hearing loss were ignored and dismissed at his 9-month check-up at the clinic and how the nursing staff just did a random hearing test and nonchalantly recorded his hearing test as normal. Similarly another participant relayed how he and his wife suspected at 3 months that their daughter had a hearing problem. After “shopping around” and between facilities, being told by various healthcare professionals that they were “*nuts*”and “*over-protective”*, the hearing loss was eventually diagnosed at the age of 9 months. Another participant, who contracted Rubella during her pregnancy had suspected her baby had a hearing loss at age 9 months old, and requested the nurses at the day hospital to check her hearing. She recalled how she was only rebutted by the nurses who“*kept saying that there is nothing wrong with her, her hearing is fine. We must give it time say so after a year………..eventually they checked it and found that she was deaf. I couldn’t believe it……… I went to lots of people and they kept on saying different things”.*

Zand and Pierce (2011:90) argues that the earlier the identification of the hearing loss takes place, the quicker the response will be in starting early intervention strategies to assist the child.

For some of these participants the loss of their perfect baby accumulated into a loss of dreams and hopes that they had for their healthy child and for themselves, leaving them in a world of sadness and uncertainty. Being well established professionals in their jobs and having planned their pregnancy, one of the participants remembered how they planned for the baby, wanted everything to be perfect, planned for preschool and even aftercare. All of this changed, and suddenly they found themselves in consulting rooms, attending speech therapy classes and lamented *“You know this is not what we had expected”.* Another participant reflected how devastated she was as a young mother when her first child was diagnosed with hearing loss and stated the following *“I also have dreams of my own, I am just here, I feel as if I am trapped….”*

Their whole future is constructed around a healthy “normal” child. All parents have dreams for their children; they want them to be happy and successful but most of all they want their children to be healthy (Moore 2009). After the diagnosis of disability, parents may tend to dwell on the past and the present, and view the future with apprehension (Kurtzer-White and Luterman, 2003) experiencing intense grief as they try to make sense of the loss of a lost future and dreams they once envisioned for themselves and their child.

In contrast with the aforementioned reaction of grief, one participant stated that she and her husband believed that their deaf child was a “*special child from Allah*” and therefore immediately embraced their child’s hearing loss. These parents found strength, hope and relief through their spiritual belief.

**Theme 3: General experiences of post-diagnosis on the way forward: "it’s a journey”**

Parents described their journey as a process of practical decisions around issues such as education, communication, independent living, practical arrangements of seeking educational and professional help. A journey of various emotions, mental and physical exhaustion, challenges, some days were filled with grief, depression and anger, and other days with acceptance, accomplishments and celebrations.

Poor communication and the lack thereof were also a central concern for all the hearing parents during their journey. They expressed the enormous communication conundrum that they faced, and how it tired them emotionally and physically. Zaidman-Zait (2008) confirms that communication between hearing parents and their child with a hearing are a contributing factor to parental stress. The communication barriers between the participants and the child with hearing loss lead to frustration, anger and irritation as some lamented: *Communication is a stress factor for me...…. I felt that I’m a failure to her because I don’t understand her I can’t communicate with her.” “….to learn sign language, to learn all these things….” no one told me about sign language classes*. Pipp-Siegel, Sedey, and Yoshinaga-Itano, (2002); Zaidman-Zait, (2008) is of the opinion that stress steps in when parents and the child with the hearing loss are unable to communicate to each other. Mothers seemed to bear the brunt as they often played the “interpreter”between the child with hearing loss and the rest of the family members. Although hearing parents expressed the need to communicate with their child, they often became impatient and dismissive in their body language towards the deaf child: *“Sometimes I am so tired that I just tell her anything which is wrong and then I feel guilty and so bad as I am actually lying to her because I am tired. Sometimes also because I don’t have the time and it is very difficult”*

Flasher and Fogle (2003) echoed the fact that often one parent takes on the responsibility to repeat and restructure information in the home, in order for all to be understood, as conversational interaction can become less through misunderstandings. Swanwick (2012:5), agree that it is often the mother that takes on the role of the effective communicator with the child and subsequently becomes the intermediary between the family and the child. Similarly mothers often extend their responsibilities to cover service, education, and advocacy needs of their children becoming targets of emotional and physical burnouts (Benzies, Trute, and Worthington, 2013). Hearing mothers, recalled their everyday frustrations, their tension, the sheer physical, mental and emotional exhaustion they experienced. One of the participants described her personal journey as a *“roller coaster of emotions”.*  Another participant’s perceived journey of motherhood after a planned pregnancy did not include a diagnosis of a disability and the additional challenges that went with when she said *“I am just tired, tired of all the struggles”* and another *“sometimes I just feel it is too much…”.*

In addition, discipline and supervision of the child with hearing loss posed a challenge for most of the participants. Often the lack of understanding and communication compounded the discipline issue for the hearing parents. Apart from the fact that disciplining their child with hearing loss was tiring and time consuming, it appeared that mothers were mostly responsible for their hearing impaired child’s discipline.

Seltzer, Greenberg, Floyd and Pettee (2001) conclude that mothers often feel overwhelmed, stressed, frustrated and angry at shouldering most of responsibility of disciplining a child with hearing loss. Hearing mothers are also limited in holding employment or participating in activities outside their homes due to the need for full time parenting of their disabled child as illustrated: “ *“I am at home all day…if I can say so, I can’t work and that makes me cross ….“I am here all week, all week in this place”*

**Theme 4: specific experiences of the way forward for hearing parents with a child with a hearing loss**

Although all the participants who took part in the study had reacted with shock, grief and denial, there were also some who were more proactive than others. Some hearing parents empowered themselves with more knowledge about the disability itself in order to assist their child with hearing loss. Others tended to go through the different emotions, the ups and downs and accepted their fate as parents of a child with a hearing loss. All the participants who took part reported to receiving little or no emotional support from professionals when initially confronted with the diagnosis. The following quotations illustrate their experiences *“I had no one to speak to; I think if I had someone to speak to that time then maybe it would be better”“……..She [meaning the mother of the child with hearing loss] needs to vent her feeling her anger and frustrations” “There was no one to really talk to; there were times that I wish I had someone to speak to”*

**RECOMMENDATIONS**

* It is recommended that health care professions assist hearing parents to understand the etiology of deafness and provide counselling to parents, family and siblings and to the child with the hearing loss.
* Organisations of the deaf should establish parent support groups and invite speakers on various topics of relevance for example on deaf culture, sign language, cochlear implants and parenting skills.
* Exposed deaf role models to hearing parents and the child with the hearing loss.
* Public awareness programmes in alleviating public ignorance.
* A cross disciplinary approach is encouraged to provide parents the necessary support in decision making to facilitate informed decisions.
* Closer collaboration between organisations for the deaf and various Universities regarding curriculum development and planning with regards to the training of social workers, psychologist, audiologist and paediatricians.
* Further research of similar nature needs to include more fathers, as their experiences could differ substantially from those of mothers.
* A study could be undertaken with deaf adults to explore and understand their experiences and dynamics of growing up in a hearing family
* Comparative study could be done with deaf parents raising deaf children, and compare their experiences to those of hearing parents

**CONCLUSION**

The main purpose of this study was to describe and explore the experiences of hearing parents whose children have been diagnosed with a hearing loss. Of significance to the study is that it highlights the challenger’s parent’s face and the need for emotional and psychological support and counselling for hearing parents. The post-diagnosis phase was experienced as an all-consuming adaptation, as family relationships, educational responsibilities, supervising of children, and communication were extremely challenging for parents. The study indicated the need for support and advice from healthcare professionals and the need to work with hearing parents, forming partnerships that are invaluable for both parents and child. These partnership can assist hearing parents with a better understanding of their child’s disability, its etiology, address the trauma of the diagnosis, the subsequent loss of an abled bodied child and supporting all parties concern. Furthermore the study relates to the need for more research in the area of deafness and the impact it has on family life.

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