

# Experiences of Hearing Parents Following Their Child's Hearing Loss Diagnosis

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## ABSTRACT

An estimated 90 per cent 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 was conducted in Cape Town, South Africa. 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 hearing parents and a child with hearing loss. Furthermore, these findings serve as guidelines for professionals working with these families.

**Keywords:** hearing parents; diagnosis; experiences; 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 World Health Organisation (2015). The latest figures from the World Health Organization (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 per cent of the population were classified with a hearing loss (Statistics South Africa 2015), however, this number did not take into account the



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number of children under the age of five years old. A study conducted by Swanepoel, Störbeck and Friedland (2009) estimated that three in every 1 000 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 suggest that 90 to 96 per cent of children born with a hearing loss are born to hearing parents (Estabrooks 2012; Fitzpatrick et al. 2013; Krywko 2012; Kushalnagar et al. 2010; Lederberg, Schick, and Spencer 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 Sjahalam-King 2013), and that parenting a child with hearing loss can be challenging and stressful (Plotkin, Brice, and Reesman 2013; Quittner et al. 2010). Although parents play a specific role in the development of their children (South Africa 1997, 5), their own journey of parenting a child with a disability also needs to be understood. Gilliver, Ching, and Sjahalam-King (2013) conclude that parents' recollections of their experiences with raising a child with a hearing loss at a young age indicate a significant grief-related response, and that parents are faced with various emotional and physical challenges when raising a child with a hearing loss. Parents revealed that they have to offer unconditional love and patience when parenting a child with hearing loss. Communication barriers seem to pose an ongoing effort on the part of the parents as the condition requires continuous explaining and is time-consuming (Thakre, Thakre, and Alone 2012). Hintermair (2006), Pipp-Siegel, Sedey and Yoshinaga-Itano (2002), and Quittner et al. (2010) therefore assert that hearing parents parenting a child with a hearing loss face a number of unique challenges that could potentially lead to elevated stress.

This article focuses on the experiences of hearing parents following the diagnosis of their child's hearing loss. Further attention is given to their emotional journey and challenges 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 parents and the child (Frank-Briggs 2012; WHO 2015). Their response to such a diagnosis often shows significant similarities to the theory of grief as pioneered by Kübler-Ross (1969). In the event of death, a very traumatic experience, there is an expectation 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 disability could bring about a different type of death, the death of important cognitive and physical functioning in a child. Initially, hearing parents are bombarded with information about education and language choices, but not provided with opportunities to express their grief, loss and challenges. Often parents' response to a child's hearing loss is grief,

confusion, sadness, disbelief, denial, helplessness and concern for the development of relationships with peers (Fellinger et al. 2009; Freeman, Dieterich, and Rak 2002; Young and Tattersall 2007) indicating a significant and dramatic emotional impact on families (Gilliver, Ching, and Sjahalam-King 2013).

Although there has been extensive literature on the impact of hearing loss on parents and family (Frank-Briggs 2012; Jackson and Turnbull 2004; Krywko 2012; Zaidman-Zait et al. 2016) this study wanted to answer the following research question: What are the experiences of hearing parents following the diagnosis of their child's hearing loss?

## Research Methodology

The goal of the study was to explore and describe the experiences of hearing parents following the diagnosis of their child's hearing loss. The objective of the study was twofold: 1) to explore the parents experiences when they found out their child had a hearing loss, and 2) to explore and describe the experiences of hearing parents caring for their child with a hearing loss.

A qualitative research approach was followed to gather descriptive data about a social phenomenon that was grounded in the lived experiences of hearing parents whose child was diagnosed with a hearing loss (Marshall and Rossman 2011; Tracy 2012). 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 and 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), and Kumar (2011) was determined by data saturation.

Data were gathered by means of individual, in-depth, unstructured interviews, which lasted 60 to 90 minutes each. The interviews were conducted at the offices of the Deaf Community of Cape Town. Participants were guided by only one question, namely "Your child was diagnosed with hearing loss. Tell me the story?" The opportunity to

reflect on the participants' experiences as explained by Creswell (2009) and Klenke (2008) provided the researchers with an opportunity of going below the surface of experiences, probing the details of the participants' emotions and the meaning that they attached to their child's hearing loss.

A thematic data analysis as suggested by Creswell (2009, 183–190) and Klenke (2008, 231) for phenomenological studies 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 Wiebe 2010). The trustworthiness of qualitative data was applied through truth value, applicability, dependability or 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 seen as credible (Creswell and Plano 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 (Denzin and Lincoln 2003; Hess-Biber and Leavy 2011; 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 Ethics Committee of the University of the Western Cape as well as the Deaf Community of Cape Town was obtained before the start 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 three hearing fathers of a child with a hearing loss were interviewed.

## Research Findings and Discussions

The findings of the study that emerged from the qualitative data were 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 below.

### Theme 1: Hearing Parents' Initial Emotional Reactions at the Time of the Diagnosis

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

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. 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. One of the participants remembered how they planned for the baby, wanted everything to be perfect, and 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 a hearing loss. She stated the following: "I also have dreams of my own, I am just here, I feel as if I am trapped ..."

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 et al. 2011). 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).

The parents who took part in this study's initial shock was followed by denial and disbelief as they struggled to accept and believe their child's hearing loss 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 nonsense.

While Brown (2012) and Northern and Downs (2002) confirm that denial or disbelief by parents is a typical reaction that will follow shock, Dare and O'Donovan (2003) reckon that denying the child's permanent disability often serves as a self-protecting mechanism for parents. Putz (2012) on the other hand, 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) alludes 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" and "I didn't want to believe the diagnosis and I for sure wanted a second opinion ..."

In addition to "shopping around" for other diagnoses, 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 (2003, 17) view this process as an important stage in the denial phase as it serves as an attempt by the parents to process and understand their child's hearing loss. Cole and Flexer (2015) therefore emphasise the importance for parents to understand the aetiology 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 ooh so heartsore.

I remember going to the bathroom at times and just sitting there and crying.

Ooh 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 a 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, Storbeck and

Wemmer (2004, 156), however, warn 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: Hearing Parents' Behavioural and Emotional Journey Following the Diagnosis of the Child's Hearing Loss

Hearing parents also reported specific emotional-behavioural responses of anger, guilt and blame after their child was diagnosed with hearing loss. Their anger was evident in expressions such as "I was very angry ... I was still very young and wanted to go on with my life", and "I was 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 parents' 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 human beings' strongest emotions, providing them with protection from emotional trauma and which often arise when they feel anxious, helpless and overwhelmed by a particular situation, such as the diagnosis of a disabled child. Kriegsmann and Palmer (2013) also assert that anger is a normal coping mechanism after being confronted with a major loss and trauma, and plead that parents 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 the child requires, 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 experiences of guilt and blame around their child's hearing loss. 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. Often hearing parents become stuck at the time of the diagnosis, asserting blame, and often tend to struggle to get beyond this point. 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, they blamed themselves and even "felt like a failure". Frank-Briggs (2012) and Dowling, Nicoll and Thomas (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.

Apart from self-blame, 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".



Another participant projected her blame for her child's hearing loss on to God and asked "if He was punishing her now for falling pregnant at such a young age". Blass (2012, 326) support the notion that some 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 2009, 164).

Hearing parents' anger and blame were also proportioned towards the negative attitude of healthcare professionals on various occasions during their journey. Anger stemmed from the way in which the diagnosis of their child's hearing loss was presented to them. One of the participants reflected that "he [the doctor] was cold by showing his back to us, ... he wasn't friendly. It was like 'I'm just doing my job here, just accept your child is deaf'". Hearing parents agreed that if the diagnosis had been presented in a gentler, more positive manner, it would have been an easier result 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 to parents' feelings could assist in their coping better (Northern and Downs 2002).

Similarly, hearing parents' anger and blame were also projected on to healthcare professionals who dismissed their 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 nine-month check-up at the clinic and how the nursing staff did a random hearing test and nonchalantly recorded the results of his hearing test as normal. Another participant relayed his and his wife's anger and blame when they suspected at three months that their daughter had a hearing problem. After seeking help at different facilities, and being told by various healthcare professionals that they were "nuts" and "overprotective", the hearing loss was eventually diagnosed at the age of nine months. Another participant, who contracted rubella during her pregnancy, had suspected her baby had a hearing loss at the age of nine months, 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, she is hearing fine. We must give it time say so after a year ... eventually they checked it and found that she was deaf. I could not believe it ... I went to lots of people and they kept on saying different things". Zand and Pierce (2011, 90) argue 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.

In contrast to the aforementioned reactions of anger, guilt and blame, 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: Hearing Parent's Challenges during Their Journey of Parenting a Child with Hearing Loss

Parents described their journey of post-diagnosis full of challenges, practical arrangements, decisions concerning education, lacking appropriate professional help and even sheer exhaustion. Some days were filled with grief, depression and anger, and other days with acceptance, accomplishments and celebrations. They recalled their lack of knowledge and information on what this journey had in store for them, but also of their enduring love, frustrations, hurt and sacrifices.

Poor communication and the lack thereof were 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 loss is a contributing factor to parental stress. The communication barriers between the participants and the child with a hearing loss lead to frustration, anger and irritation as some participants 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”, and “... to learn sign language, to learn all these things ... no one told me about sign language classes”. Mothers seemed to bear the brunt as they often played the “interpreter” between the child with a 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) agrees that it is often the mother who 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 thereby becoming targets of emotional and physical burnout (Benzies, Trute, and Worthington 2013). Shohov (2004) therefore concludes that hearing mothers experience extraordinary stress in parenting a child with a hearing loss. Most of them are also limited in holding employment or participating in activities outside their homes owing to the need for full-time parenting of their disabled child. Hearing mothers who took part in the study recalled their everyday

frustrations, their tension and the sheer physical, mental and emotional exhaustion. One of the participants described her personal journey as a “rollercoaster of emotions”. Another participant's perceived journey of motherhood after a planned pregnancy did not include a disabled child and the additional challenges when she said “I am just tired, tired of all the struggles”, and another who said “sometimes I just feel it is too much”.

In addition, discipline and supervision of the child with hearing loss posed a significant 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 a hearing loss was tiring and time-consuming, it appeared that once again, mothers were mostly responsible for their hearing-impaired child's discipline. Disciplining a child with a hearing loss also caused tension and stress between the parents who disagreed on disciplinary measures and those who did not support each other. In contrast, one participant confirmed that the strong marriage bond between her and her husband helped them to cope with their daughter's discipline and supervision.

Seltzer et al. (2001) conclude that mothers often feel overwhelmed, stressed, frustrated and angry at shouldering most of the responsibility of disciplining a child with a hearing loss. Hearing mothers are also limited in holding employment or participating in activities outside their homes owing 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 ...”, and “I am here all week, all week in this place”.

Scholastic adjustment and decisions about education choices also presented a challenge for the participants. Some of the participants were anxious and concerned about the quality of education their child would receive and whether the education would prepare their child for life beyond school, beyond their care and independent living.

#### Theme 4: Hearing Parents' Specific Experiences on the Way Forward

Although having a child with hearing loss was an extremely challenging journey for most of the hearing parents, the majority of them realised they had to adjust their way of life in order to meet the needs of the child. Despite parents' ongoing sense of grief and loss, some were more proactive than others by empowering themselves with more knowledge about the disability itself in order to assist their child with a hearing loss. They did research on the internet, joined “blogs” for hearing parents with deaf children, visited professionals and facilities and some even joined the governing body of the school attended by their hearing-impaired child. They familiarised themselves with their child's audiogram and the aetiology of their child's hearing loss and read as much as they could about the topic. They learned about the deaf culture, communication skills and sign language. These attempts seemed to empower the participants and encouraged their self-esteem and confidence in their ability to bring up a child with a hearing loss.

Taking control of their journey seemed to have a positive disposition to their experience that contributed to personal and family change and growth. Although they did not choose the particular journey that they found themselves on, empowering themselves assisted them to progress more easily through the stages of grief (Szarkowski and Brice 2016). Hintermair (2006) postulates that when people empower themselves, they are able to take control of their own affairs, thus discovering their own strengths and capabilities. Empowerment of deaf and hard-of-hearing people therefore begins with empowering the families into which they are born.

Other parents tended to go through the different emotions, the ups and downs and it took longer to accept their fate as parents of a child with a hearing loss. All the participants who took part in this study reported receiving little or no counselling after their child was diagnosed with a hearing loss. The participants advocated the need for counselling, to speak about their experiences, and to vent in a safe environment that would not cause harm to themselves, their child with a hearing loss or other family members. Hearing parents also indicated that they lacked parental guidance and support from the helping professions. They portrayed their lack of professional intervention by means of the following:

I had no one to speak to.

If I had someone to speak to that time then maybe it would be better.

There was no one to really talk to; there were times that I wish I had someone to speak to.

... no one to vent my anger and frustrations.

Likewise a need was expressed for healthcare workers to be empathetic towards hearing parents and not to be dismissed or rebutted when expressing their concerns as hearing parents. English (2008) perpetuates the notion that unbeknown to audiologists, they assume the role of the teacher as they provide new and unfamiliar information to hearing parents who have taken on the role as learners. Thus it is evident that audiologists as well as other healthcare workers play an important role in providing information that is accurate and reliable, which then enables parents to make informed choices and to take an active role in their child's development (DesGeorges 2003; Young et al. 2006).

Hearing parents needed guidance concerning educational choices and identifying an appropriate school based on their child's specific needs. Some parents felt that educational choices were made on their behalf on the basis of their own ignorance about hearing loss and while still overwhelmed by grief. Hearing parents pleaded for a greater partnership between themselves, schools or teachers and healthcare workers and were of the opinion that supportive relationships between the different stakeholders could act

as a safety net. It also became evident that hearing parents' finances and socio-economic status can be a contributing factor to coping and planning for the child's future.

## Recommendations

- It is recommended that healthcare professions assist hearing parents to understand the aetiology of deafness and provide counselling to parents, family and siblings and also 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.
- Deaf role models should be exposed to hearing parents and the child with the hearing loss.
- Public awareness programmes should be launched to alleviate public ignorance.
- A cross-disciplinary approach is encouraged to provide parents with the necessary support in decision-making to facilitate informed decisions.
- Closer collaboration should be established between organisations for the deaf and various universities regarding curriculum development and planning with regard to the training of social workers, psychologists, audiologists and paediatricians.
- Further research of similar nature should 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.
- A comparative study could be done with deaf parents raising deaf children, and compare their experiences to those of hearing parents.

## Conclusion

The findings of this study have shown that the experiences of hearing parents whose children have been diagnosed with a hearing loss are facing significant challenges in the South African context. Of significance is the lack of emotional and psychological support and counselling for the parents. The post-diagnosis phase was experienced as an all-consuming adaptation, as family relationships, educational choices, disciplining the child with a hearing loss and communication barriers were extremely challenging. Thus the study indicated the need for healthcare professionals to work hand-in-hand with hearing parents, and forming partnerships to the benefit of the child with the hearing loss. These partnerships can assist hearing parents with a better understanding of their

child's disabilities, dealing with the trauma of the diagnosis and the subsequent loss of an able-bodied child, and supporting all parties concerned.

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