

# What We Can Learn From Hearing Parents of Deaf Children

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Hearing parents of deaf children face stresses and demands related to parenting a deaf child, including difficult choices about language, technologies, education and identity for their children (Marschark, 1997). To date, few researchers have discussed the unique challenges faced by this group. Through a series of semistructured, in-depth interviews with 18 parents, this study investigated the experiences of hearing parents of deaf children spanning various life stages. A phenomenological approach identified 5 themes most pertinent to understanding their experiences. Each theme offers insight, particularly for professionals, into the distinctive issues that might arise at the time of diagnosis of deafness and reveals the challenges hearing parents face when confronted with a barrage of decisions, including choice of oral or sign language, mainstream or special deaf education, and identity with the hearing or Deaf community. The central message from this work is to inform hearing parents of deaf children and professionals working with these parents of the likely challenges that they may face.

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The most accurate synthesis of preexisting and new data on population demographics shows that 90% of deaf children are born to hearing parents (Mitchell & Karchmer, 2004). Most hearing parents of deaf children have no experience of deafness prior to the birth of the deaf child, and these parents usually experience the diagnosis as a traumatic event (Brand & Coetzer, 1994; Calderon & Greenberg, 1993; Henggeler, Watson, Whelan, & Malone, 1990). Despite advances in the last 10 years, including early detection of congenital deafness (Nelson, Bougatsos, & Nygren, 2008) and early cochlear implantation (CI; Anderson et al., 2004), new hearing parents of deaf children face multiple challenges (Burger et al., 2005; Hardonk et al., 2011; Spahn, Richter, Burger, Löhle, & Wirsching, 2003).

As the child is born into a majority hearing world, parents must confront matters such as investing time, building trust, readjusting expectations and engendering tolerance and acceptance of those differences (Young, 2010). Feelings of grief and loss among hearing parents of a deaf child as well as stress and painful emotions have been widely reported (Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007; Hardonk et al., 2011; Young & Tattersall, 2007). Mixed method (Punch & Kidd, 2001) and case study research (Simser, 1999) reveal the considerable strains on families, including the grief, guilt, denial and anger experienced by some mothers.

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The parent faces choices with language, technologies, education and identity. Parental decisions have to be made, and often within a certain timeframe, such as the so-called ‘window of opportunity’ for language development (Pallier, 2007), although this ‘critical period’ hypothesis is debated in the neuroplasticity literature (Bates, 1999; Mundkur, 2005). Although one might anticipate that communication difficulties in hearing parent–deaf infant dyads would increase the risk of insecure attachment, the impact of hearing impairment on attachment remains unclear in the literature (Lederberg, 1993; Lederberg & Prezbindowski, 2000; Marschark, 1993; Weisel & Kamara, 2005).

Early CI is generally linked with superior oral language development and education (O’Donoghue, 1999; Stacey, Fortnum, Barton, & Summerfield, 2006). The long-term outcomes (Marschark, Rhoten, & Fabich, 2007), however, including the implications of the limited range of language choices offered, the absence of associated aspects of deaf culture (Hardonk et al., 2011; Young, Jones, Starmer, & Sutherland, 2005) and the ethical issues involved, such as the right to be deaf and not viewing deafness as a disability (Balkany, Hodges, & Goodman, 1996), remain uncertain and require further investigation.

Choices that the hearing parents make, from their cognitive and language development to socialisation and cultural identity, will influence the entire course of their deaf child’s life (Calderon, 2000; Marschark & Spencer, 2010; Simser, 1999; Vaccari & Marschark, 1997). The family is critical for the social and cognitive development of a deaf child (Danek, 1988; Greenberg & Kusche, 1989; Marschark, 1993; Warren & Hasenstab, 1986), and a highly stressed family can foster poor social competence in the deaf adolescent (Watson, Henggeler, & Whelan, 1990). Indeed, being accepted by the family is a crucial influence on the healthy development of a child’s identity (Hadjikakou & Nikolarazi, 2007). Despite the lack of literature on the experiences of deaf parents of deaf children, research suggests that they compare with those of hearing parents of hearing children (Marschark & Spencer, 2010).

Detection of congenital deafness in neonates generally enhances the benefits of early care interventions (Nelson et al., 2008; Yoshinaga-Itano, 2003). However, despite access to a universal newborn hearing screening (UNHS) program since 1998 and to cochlear implantation and support services for early care, parents of deaf children in Flanders reported experiencing confusion, disbelief, disappointment and uncertainty (Hardonk et al., 2011). This study focused on one time period of ‘early care trajectory’, from diagnosis to reduction in rehabilitation care (i.e., ‘when satisfactory oral language development is reached and/or the beginning of school’, Hardonk et al., 2011, p. 319).

The current study attempts to expand this knowledge base to a sample of hearing parents of deaf children of a wide age range, from childhood to adulthood, in Western Australia (WA) using an in-depth qualitative research design (Gill & Liamputtong, 2009; Grbich, 2007). It was hoped that deeper insights might be obtained by referring to the knowledge and experience of parents gained over an extended period of their children’s lives, from infancy to adulthood.

In July 2010, a UNHS-based automated auditory brainstem response (AABR) program was introduced in WA. Childcare professionals inform the parents if the second AABR test requires referral to an audiologist. Different follow-up services (Australian Hearing, ear, nose and throat departments in hospitals, West Australian Institute of Deaf Education [WAIDE] and Telethon Speech and Hearing) offer multidisciplinary care, fitting of traditional hearing aids and referral for CI (Ear, Nose and Throat Advisory Group, 2011). WA is an ideal setting to analyse the perspectives of parents of deaf children of varying ages born before 2010. Conducting the study in WA may help inform professionals in the fine-tuning of interventions beyond early diagnosis in order to minimise parental distress,

and also enhance the emotional and informative support. Furthermore, the current study acts as a complementary study to Hardonk et al.'s (2011) findings, in which all parents interviewed had children born after UNHS was implemented.

Insights can be gained from a comprehensive investigation of parenting of a deaf child over an extended period, beyond diagnosis and early care (Burger et al., 2005; Spahn et al., 2003). First, a better understanding of what it is like to be a parent of an older deaf child could help parents of a younger deaf child shape care-related decisions as well as influence their parenting and parental self-care by seeking professional support. Second, listening to parental experiences related to different developmental periods of the child may inform professional healthcare practice. Third, in contrast to existing studies, which focus on the voices of the mother (Hardonk et al., 2011; Punch & Kidd, 2001), this study addresses both the mothers' and fathers' experiences separately. Finally, extending our understanding of the parental role to a lifelong care framework helps to assess priorities and inform future research.

## Method

### *Study Design and Data Collection*

Within the qualitative paradigm, a phenomenological framework was utilised (Creswell, 2007), as it enabled the researcher to elucidate the meanings and common features associated with the lived experiences of a hearing parent of a deaf child (Starks & Brown Trinidad, 2007).

Interviews were conducted with English-speaking hearing mothers and fathers or other responsible primary carers of children with congenital hearing loss. All of the children had normal cognitive development, some with appropriate therapy and educational intervention. The participants were required to be either the parents or the primary carers of a deaf child from birth and to be residing in WA. As UNHS in WA was introduced in 2010, only children born before that date were included. No upper age limit at time of interview was set on the children, as the researcher hoped to elucidate a long-term picture of parenting over the life span.

A combination of sampling methods was used for recruitment. Attendance at meetings and lectures of the WA Deaf Society and WAIDE provided the researcher with opportunities to discuss the study and to recruit participants for a snowball sampling technique (Liamputtong & Ezzy, 2005). In total, 18 participants were interviewed: 10 women (nine mothers and one grandmother, who was the primary carer) and eight fathers. All families described themselves as middle class and identified as Caucasian (16), Black (one) or Asian (one). Participants had between one and five children, and all were partnered or married. One couple had two deaf children. All others had one deaf child. The relevant details of the children are summarised in Table 1.

Two methods were combined in the data collection phase. Firstly, 18 semistructured, in-depth, individual interviews were undertaken; these are often utilised within the phenomenological paradigm (Moustakas, 1994) and were designed to reveal the parents' experiences according to particularly salient themes. As a starting point, to stimulate the interviews and to help the parent to navigate their memory of their experiences, participants were asked to reconstruct events, decisions and outcomes of those decisions chronologically in the life of the child. The researcher asked additional questions from a checklist, on the topics of diagnosis and reaction, decisions on language, technologies, education and identity, and recommendations to other parents and professionals in the field (Silverman, 2013).

**TABLE 1**  
Demographic Information Regarding the Deaf Children of the Hearing Parent Participants

Child	Gender	Age of child at time of interview (years)	CI status	HA status	Aetiology	Age of identification of deafness	Daily mode of communication	Educational setting of child at time of interview
A	M	22	No	HA at 4 years	Congenital	4 years	Auslan (started at age 11)	University
B	F	17	No	HA at 6 years	Congenital	2 years	Auslan (started at age 6)	University
C	M	15	CI at 3 years 2nd CI at 9 years	No	Congenital	11 months	Auslan (started at age 4) & verbal	Mainstream school
D	M	13	CI at 3.5 years	No	Congenital	7 months	Verbal & learning Auslan at time of interview	Mainstream school
E	M	3.5	No	HA at 11 months	Congenital	6 months	Auslan (started at age 1)	WAIDE
F	F	19	No	No	CP <sup>a</sup>	8 months	Auslan (started at age 3)	N/A
G	F	9	CI at 4.5 years	No	CP	3 years	Auslan (started at age 3) & verbal	Mainstream school
H	F	12	No	HA at 6.5 years	CP	6 years	Auslan (started at age 7) & verbal	WAIDE
I	F	11	CI at 6 months <sup>b</sup>	No	Goldenhar syndrome	6 months	Auslan (started at age 7) & verbal	Mainstream school
J	F	30	No	No	Congenital	4 years	Auslan (started at age 17)	N/A
K	F	21	CI at 7 years	No	CHARGE	3 years	Auslan (started at age 15) & verbal	N/A

Note. CI = cochlear implant; HA = hearing aid; CP = cerebral palsy.

<sup>a</sup>Cerebral palsy associated deafness. <sup>b</sup>This child had a second cochlear implantation when she was 4 and a half years old, but her grandmother reported that it was put in without MRI testing. It was later found that she had nerve damage in that ear.

Events	Birth to early childhood	Late childhood to current age
Access to information about language choices, such as oral, Auslan		
Communication in the home		
Communication in the community		
Access to information about education of the deaf		
Identity issues		
Recommendations to other parents on this issue		
Recommendations to professionals		

**FIGURE 1**

(Colour online) Example of “Language, Education and Identity” Grid.

Second, because the events that the parents were being asked to recall had taken place over a time span ranging from 3.5 to 30 years before the interview and therefore liable to be tainted by recall bias, a life-grid method was employed (Blane, 1996). The life grid is a chronological plot in which the span of the child’s life is represented visually. Four grids plotted different aspects of the child’s life: ‘finding out he/she was deaf’, ‘early interventions and support’, ‘language, education and identity’, and ‘challenges at various stages of development’. Every grid had columns representing the life span of the child from birth to the time of the interview (adjusted for the particular child’s age). Different types of events were noted in rows. Figure 1 represents an example of the language, education and identity grid. Events were registered in each cell according to the aspect of life, the circumstances, and when it occurred. This scheme was used to facilitate and validate the chronology, dates, order of events, and general consistency of retrospectively collected information (Berney & Blane, 1997).

Each interview was audio-recorded digitally and lasted approximately an hour. The experimental design followed protocols for obtaining informed consent. The researcher led the conversation at each interview and reflexivity was maintained throughout, so as to minimise the potential for researcher bias. The researcher kept a journal to record thoughts, feelings, and impressions encountered during the data collection and reduction process. This assisted in identifying biases held by the researcher and achieving clarity. The Edith Cowan University’s Human Research Ethics Committee approved the research.

**TABLE 2**

Themes and Component Points of the Experiences of Hearing Parents of Deaf Children

Themes	Subthemes
1. Trauma of diagnosis of deafness	Different reactions of father and mother Need to grieve
2. Model of deafness	Medical model or sociocultural
3. Australian Sign Language	Deaf Culture, Community and Auslan Concerns with Auslan
4. Cochlear implant	CI and oral language training
5. Needs of the child at various life stages	

### Data Analysis

Interviews were transcribed verbatim and analysed using the preliminary data analysis technique outlined by Grbich (2007). Immediately after each interview, notes were made relating to the main topics raised by the participant. These notes then evolved during the transcription process as sections of text relating to the parents' experiences and were assigned a short notation. This 'preliminary analysis' was a valuable precursor to the thematic analysis process as it highlighted potential categories (Grbich, 2007).

After transcription, all interviews were analysed using thematic analysis (Braun & Clarke, 2006; Green et al., 2007). These were read repeatedly to facilitate immersion in both the content and shared context of each individual interview. Transcriptions were considered both individually and concurrently. Saturation of data was evident after several interview transcript reviews were conducted (Josselson & Lieblich, 2003).

Two additional methods were used to enhance methodological and interpretative rigour. First, participants were invited to a parents' gathering at the WA Deaf Society approximately one month after interviewing was completed. Along with other relevant issues, the themes that emerged were discussed and identified as reflecting the participants' own experiences (Creswell, 2007; Murray, 2003). This focus meeting confirmed that the parents' experiences had been captured (Mertens, 2009). Seven of the parents attended the meeting and agreed that the themes identified accurately reflected their lived experiences. Those who did not attend were contacted by email and also confirmed their agreement. Second, researcher triangulation was performed where transcript themes were examined, discussed and agreed upon by unanimous consensus with three independent experts from WAIDE, WA Deaf Society, and the Deaf Interest Group of the Australian Psychology Society (Creswell, 2007; Smith, 2003). Direct quotations were used to ensure thematic conclusions were supported in rich detail (Liamputtong & Ezzy, 2005).

### Results

From the 18 verbatim transcripts, 112 significant statements were extracted and their formulated meanings were clustered into five themes. Table 2 outlines the themes and their component points, which are further elaborated in the text. Table 3 contains parent recommendations to other new hearing parents and professionals, and examples of significant quotes are included to expand the findings. Differences in perspectives of the parents can be accounted for by reference to their child's background (see Table 1). Pseudonyms are used.

**TABLE 3****Parent Recommendations to Other New Hearing Parents and Professionals****Accept that the child is deaf**

## Significant Statements

*Right at the beginning I didn't want to be inundated with deaf people, to be honest. I'm ashamed to say that deaf people did not exist in my world. I had images from deafness in the media, which were all negative and suddenly I thought I don't want a little boy who talks funny. And I didn't even know all those negative things were in me. And I wasn't ready to be faced with deafness. I was still in denial.* (Mother of E)

*Do not view deafness as the disability. There are many people who are deaf and they are happy, they really embrace it. These people are happy and they don't see this as a disability. And we shouldn't either.* (Father of A and B)

*We never said to Kitty [pseudonym used for child J] that she had a disability, she went to school when she was five and she came back and she said 'Am I disabled?' And we said 'No you're deaf. You are not disabled'.* (Father of J)

**Recommendations to professional about technical support (CI and HA), language, education and identity choices**

## Significant Statements

*Don't just give a pamphlet to the parents, understand how the family ticks, and listen to the parents, because they know their child best.* (Mother of C)

*Never assume that technology will cure all. When you are discussing options with parents, find out how a family ticks.* (Mother of A and B)

*The medical profession has to be bilingual; they have to know about Australian Sign Language. They have to know it's an option. They have to offer it to you.* (Mother of C)

*Doctors need to understand the culture of deafness. And treat it more as a life choice, as a culture, rather than as a medical problem.* (Father of E)

**Get informed about deafness**

## Significant Statements

*Get up to date knowledge on deafness. Contact either a parent who has a deaf child or someone who knows about deaf issues. By meeting deaf adults, you get an insight into how a deaf person thinks and how they view the world and it also allows your child to have adult deaf models to emulate. Get a support network around you. Contact the Deaf Society, contact Speech and Hearing, contact everyone. Contact people you can believe. Then set them up as your network. Your child's life is depending on it. The people on the team have to be bilingual.* (Mother of A and B)

*It is useful to meet hearing families with deaf children a few years older than your own.* (Father of D)

**Give the deaf child as many opportunities as possible**

## Significant Statements

*If you give them the opportunity then you do not need to take responsibility for where they end up. It is their choice.* (Father of C)

**Understand the impact of deafness on the whole family**

## Significant Statements

*It put a strain on our marriage for sure.* (Mother of C)

*As my husband and I worked together on this, it made us an even stronger unit.* (Mother of G)

*The whole family has to be involved and work with patience and understanding.* (Father of A and B)

**Theme 1: Trauma of Diagnosis of Deafness**

All discussed the trauma of being informed that their child was deaf. 'It was the worst day of my life', the mother of H reported. Many were informed in what they considered an unprofessional manner. The mother of E overheard nurses discussing the 'profound deafness' of her child in the corridor.

***Different Reactions of Fathers and Mothers.*** Fathers tended to see the deafness in a pragmatic way. Father of E noted, 'It was very much "we can fix it". We will give him hearing aids and that will fix the problem'. The father of B simply stopped speaking to his daughter once he found out she was deaf. The mothers of C, D, E, and G reported sadness

at their lack of bonding with the child. The reaction to the diagnosis of all mothers was emotional and they sought emotional support.

**Need to Grieve.** The need to grieve was expressed by all parents. The parents of the younger children acknowledged that they did not as yet have enough time to grieve. With the pressure of having to make choices about such concerns as communication and school, the mother of E expressed that ‘there was no permission to grieve’. Those whose children were in their late teens or early twenties at the time of interviewing found that the grieving process took time. The mother of C said, ‘There is a long process of mourning; sometimes you think that the process is finished and again there are difficulties. As the years go on things get a bit easier’. The mother of two deaf children, A and B, now in their late teens and early twenties, said that ‘thinking back it impacted more than I realised. Because at the time I thought, “what do I do now?” That grieving process I didn’t go through. It surfaced 10 and 15 years later’.

### *Theme 2: Model of Deafness — Medical or Sociocultural Model*

Although individuals within the deafness continuum have their unique personal identity, the diversity of deafness and its meaning is often managed by situating deafness within distinct models (Padden & Humphries, 2005; Scheetz, 2003; Woodward, 1972). The medical view of deafness focuses on the hearing loss itself and deafness is seen as a disability. The sociocultural model focuses on the social and cultural experience of being deaf in a society in which the majority of individuals are hearing. Deafness is seen as a linguistic and ethnic minority culture.

The parents agreed that deafness should not be viewed as something ‘to be fixed’ (father of E), or as ‘a medical problem’. The medical approach reduces the child to a ‘pair of ears’ (mother of E) needing repair. The mother of H summarised her feelings on the medical approach:

*I would like the whole process to have been different. It was like we’ll fix it with hearing aids. And they will fix it with the cochlear implants later. I would like more information as to what the kid’s life would be like. They told us that ‘when you stick hearing aids in, then everything will be all right’.*

### *Theme 3: Australian Sign Language*

Sign language (or sign) is a language that uses manual communication and body language to convey meaning, possesses its own morphology and syntax, and supports the full range of expression of thought as spoken language can (Schembri & Johnston, 2013; Stokoe, 1960). Just as there is no one universal spoken language, there is no one universal sign language. Statements in this paper that mention sign or sign language refer to Australian Sign Language (Auslan), the sign language of the Australian Deaf community. The Australian Federal Government recognised Auslan as a community language in 1991 in the Australian Language and Literacy Policy (Australian Government Department of Employment, Education and Training, 1991), and the first Auslan dictionary was published in 1989 (Johnston, 1989). Australian deaf children use a range of communication modalities dependent on the age of onset of hearing loss, family communication and school placement. These modalities include Auslan, Signed English (a form of sign language using English syntax rather than the syntax of Auslan), and oral/written English.

All the parents, when asked what they would do differently if they had their time back, said they would learn Auslan and teach it to their child as soon as possible. The mother of E noted that Auslan gave the concept of language to the child: ‘Sign gave him immediate

access to language'. Many parents said that introducing Auslan to the child opened up a line of communication and that frustrations were reduced.

*It was basically all medical, a waste of time until we learnt sign language. Once we learnt to communicate with Paula [pseudonym used for child B], communicate all the time, fully with Paula, all the problems went away; the anger, the aggression, the distance. Once we had a full communication with her, all the problems dispersed. (Mother of child B)*

**Deaf Identity, Deaf Culture and Auslan.** In the signing environment the child was accepted for what he was, and 'not something that needed to be improved and changed' (mother of E). Learning sign gave many of the children a sense of identity and confidence.

Auslan was reported to be an important passport to the Deaf community, which comprises deaf individuals who share common beliefs, values, and a common way of interacting with each other and with hearing people (usually through sign language). Parents of children who signed saw them as being bicultural, but more comfortable in the Deaf community. In general, those parents who knew sign language were more integrated into the Deaf community and felt more accepted than those who had poor or no signing skills. Meanwhile, parents of those children who used *both* oral and sign communication (Auslan and/or Signed English) tended to gravitate to the hearing world. The mother of child C, who communicated comfortably with both sign and speech, noted that 'he is not a capital *D* deaf. He sees himself as a small *d* deaf.

When the whole family adapted to deafness by learning Auslan and integrating themselves in the Deaf community, as in the case of the family of A and B, communication, self-esteem and education were enhanced. Both A and B were studying at university at the time of the interview.

**Concerns with Auslan.** When some of the children got an opportunity to learn more signs at school they very quickly became more fluent than their parents. This caused frustration for both child and parents.

*I'm getting more tantrums now, because her sign is so much better than mine. There is a lag. I did classes at TAFE. But she has gone way ahead of me. When Nuala [pseudonym used for child I] comes from school, when she has learnt new signs and she is signing to me, I don't understand. And then she pulls my ears down because she reckons I can hear so maybe I will understand the signs then. (Carer of child I)*

When the child reached the age of 17 or 18 and was no longer in school, it was difficult to find people with whom to communicate through Auslan, especially if their signing was poor, as most Australians are unable to converse in Auslan (Johnston, 2004).

It was often difficult to find someone to teach the child to sign Auslan fluently, especially for those living in a remote area. The mother of H, who lived in a rural setting, learnt Auslan from a book and therefore often made the signs incorrectly.

*I had a booklet to work from Auslan, which I proceeded to do wrong, not all of them, but some of them and that's what I worked from. I had no exposure to deaf people. We were living in the countryside.*

Parents found it hard financially to have a teacher come to the family and teach them Auslan.

Some hearing siblings took Auslan on and became bilingual, whereas others rejected it. Some parents 'still felt a bit guilty' (father of J) about not having learnt Auslan better, especially when their children became fluent and they couldn't communicate with them as fluently as they would have liked.

#### *Theme 4: Cochlear Implant*

Parents' satisfaction with outcomes for CI varied. On the positive front, Parents of C and D mentioned that the child was more coordinated after the CI operation. Indeed, the mother of C noted:

*The pivotal part of Michael's [pseudonym used for child C] development, I believe, was getting the cochlear implant. Because he was so frustrated he couldn't make us understand him. It may have been six months, but everything clicked on. He realised that there were words for what he wanted. If he wanted to drink there was a word for drink.*

Many parents, however, reported pressure to have an implant from both the medical world and marketing consultants. The parents of E resented booking MRI appointments without their endorsement, and felt 'almost harassed' into having a CI. They 'felt battered and bruised by the system'. The father of E noted that the doctors 'were incredulous that I would do anything besides the CI'. E's parents abandoned the CI route. The need to digest the fact that their child was deaf and the need to grieve meant that many parents did not want to be rushed into making choices too soon. The mother of G, aged 9 at time of interview, regretted getting the implant, noting

*I think the stress of the operation plus hearing were very stressful for her ... I am still not convinced that it was the right thing to do for her. She would still prefer not to wear it and she loves her peace. She does hear the sounds when she has the CI on. But as soon as she comes home from school, she wants it off. I don't know if we are being a bit slack that we just let her not wear it. But she gets stressed out with all the background noise.*

The father of D reported dissatisfaction with the technical support in the school setting and manufacturer backup. Parents of A, F and J reported that their deaf children were asked if they wanted the implant when the children reached their teens and twenties, and the children were very adamant that they did not. The children felt they were already functioning quite well without it.

**CI and Oral Language Training.** The mother of C felt that the reason for her son's success with the implant was her intensive language training with him.

*I worked with him every day at home. I would talk to him all the time. We would go shopping he would pick something up, and he would learn the words ... apple, orange ... etc. I would never stop. People thought I was mad. He became a lot less frustrated ... It also helped his confidence.*

C's parents were told by the school not to sign or gesture with him. They did not do so for a while. His mother felt, however, that having some signs to confirm meanings when things were unclear would help communication, so she learnt Auslan and so did her son. Having both sign and speech not only helped his communication, but also opened him up to having deaf friends. He is bilingual.

The father of K noted, 'There is no point putting the CI into a child if they are not going to do the practice for the oral. It's not going to work'. D's parents were not aware of the intense oral practice necessary to support CI. Because child D had not had the same intensive language training as C had, he was often unable to follow the gist of conversations. At 15, his mother now believes he needs to learn sign so as to enhance his communication skills. He has poor syntax and only his parents and one friend can really speak to him as they speak his language, what she called 'Martin speech' (pseudonym used for child D).

### Theme 5: Needs of the Child at Various Life Stages

Children have different needs at different stages of life. At 18 months, the mother of H said that pointing to things and gesturing no longer satisfied communication needs and both she and the child became frustrated and needed a language. Many parents noted that disciplining the deaf child had to be done in a different fashion to hearing children.

Another time of change is in early adolescence when ‘children change the way they play, they all sit around. They don’t play, they sit around and talk about boys’ (mother of B). A further challenge in high school was English comprehension, syntax, punctuation, and subjects that involved a lot of conceptual reading. Parents of boys in particular tended to focus on sports and avoid the difficulties of subjects that required a more complex form of communication.

Parents, notably those of older deaf children, stressed the importance of remembering that the child’s needs are long term. The father of A and B noted that

*In the end they have to live their lives. We will be with them until they are 17, 18, 19 . . . and then they are out. But they have another 70 years as their own people. The school environment is good but then they have 60 years in the community.*

## Discussion

In this study, hearing parents shared their emotional and practical experiences of parenting a deaf child. The impact of being informed that one’s child is deaf and the grief and sometimes unintended rejection towards the child that parents reported, are consistent with previous findings (Hardonk et al., 2011; Punch & Kidd, 2001). Two mothers of deaf children (A and B, and J), now in their late teens and early twenties, noted that they were only now coming to terms with the grieving process and that this sometimes takes many years.

An important contribution to the field was the inclusion of the fathers’ voices, in contrast to previous studies such as those conducted in England (Young & Tattersall, 2007), Belgium (Hardonk et al., 2011) and Canada (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008) where UNHS had already been implemented, which focused only on the mothers or on the parents as a dyad. There was a consistent disparity in the way the mothers and fathers adjusted to the identification of deafness in their child. The mothers employed an emotional strategy, whereas the fathers consistently had a pragmatic reaction. This difference sometimes led to marital tension. The mother of child D noted, ‘marriages can fail; it is a tough road. Males look at it very differently’. Mothers displayed heightened sensitivity and were aware of the struggle with their motherhood identity (Kobosko & Zalewska, 2011).

Added to the distress of their new role, parents reported being poorly informed of their child’s deafness and were often confused by the medical terminology used by the health professionals. Counselling would have been useful, in the form of meeting with other parents who had been through the same experience or talking with someone who has an understanding of deafness from many perspectives and, ideally, some personal experience with it. This is in line with findings by Hardonk et al. (2011), where one of their participants referred to ‘some sort of in-between step, somewhere that you could turn for some support’ (p. 313). Access to personal and social resources is associated with significantly lower stress experiences (Hintermair, 2006; Young & Tattersall, 2007). Parents reported that they could benefit from behaviour management strategies at various stages of the child’s development. These findings indicate the necessity for parents of children diagnosed with deafness to have access to tailored counselling services.

According to Talay-Ongan (2000), the authoritarian professional model is no longer the preferred option in special education. Empowerment of families and trust and respect are achieved by involving the parents in a relationship of partnership with the professionals. Theme 2 is consistent with this viewpoint. Gaining informed advice tailored to the particular family and child, and listening to the parents, as well as the adoption of a sociocultural perspective of deafness by the professionals, where deafness is celebrated rather than merely tolerated, were viewed as important. This attitude will no doubt empower the parents and facilitate support structures for the families (Bortoli & Bynes, 2002; Young & Tattersall, 2007). Musselman and Kircaali-Iftar (1996) hypothesised that children with advanced spoken skills have parents who view deafness in their child as a challenge and accept it, whereas children with low spoken skills have parents who view deafness as a difference to be accommodated. DesGeorges (2003) noted that the end point of the so-called 'adjustment' to having a deaf child is not acceptance, but positive action in the form of advocacy for both the child and family. Indeed, families who accept and embrace their child's deafness have deaf children with higher self-esteem than those that do not (Bat-Chava, 2000; Maxwell-McCaw, Leigh, & Marcus, 2000). Communication between deaf children and their families is influenced by familial adaptation to deafness. Difficulties in communication between hearing parents and their deaf children may result in less than optimal psychological health in the children (Cornes & Brown, 2012).

With regard to communication mode, the 'either/or' approach to spoken or sign was described as dissatisfying, unreasonable and unhelpful to parents. Other studies have reported similar findings (Archbold, Sach, O'Neill, Lutman, & Gregory, 2008; Watson, Henggleer, & Whelan, 1990). Theme 3 echoes the report by all participants who, when asked what they would do differently, said they would learn Auslan and teach it to their child as soon as possible (see also Spencer, 1998). Dissatisfaction with not being offered sign language as a viable option by the professionals and the cultural implications of this repeat previous findings (Hardonk et al., 2011; Young et al., 2005). UNHS increases the emphasis on development of exclusively spoken language (Archbold & Mayer, 2012) and indeed the expectation of more normalised spoken language development among parents of deaf children (Leigh, 2008). Sign is often only introduced in these contexts when the child's verbal linguistic skills fail to develop as hoped (Mayer & Leigh, 2010). Thus access to sign language is compromised in terms of optimal timing and input. Indeed, it has been recommended that all deaf children with CI have access to both sign and spoken languages so as to exploit both modes of language simultaneously (Lucas & Valli, 1992).

Five of the children had CI, but parents of only one of them felt that outcomes from implantation had met their expectations and that child, C, had intensive continuing oral training by his mother to the point where the child's prosody was excellent. C had also learned Auslan. High levels of language competence among deaf adolescents has been found to be related to mothers' investment in oral language training (Kobosko & Zalewska, 2011). Zalewska (1998, as cited in Kobosko & Zalewska, 2011) noted that mothers of deaf children develop an identity as a teacher and speech-clinician. The comments of the four sets of parents who were less satisfied with the implant reflect the fact that many parents do not always recognise how much 'work' is involved in teaching their child sound recognition, language and speech development when there is early CI (Svirsky, Robbins, Kirk, Pisoni, & Miyamoto, 2000). Parents reported that they were given unrealistic expectations of the implant's potential, reiterating previous findings (Archbold et al., 2008; Hardonk et al., 2011). The dissatisfaction with the management of the technology of the CI in the classroom, as noted by the father of child D, is an issue that has been raised by others (Archbold & Mayer, 2012; Archbold & O'Donogue, 2007; Ben-Itzhak, Most, & Weisel,

2005). It is not known how much exposure to auditory spoken language is necessary for children to experience optimal benefit from CI (Spencer & Marschark, 2003). Parents believed that as soon as their child received the implant he or she would hear, much like one might put on glasses to improve vision, and therefore there would be no issue about grief or loss. However, they were blindsided and experienced emotional upheaval. This would imply the need for counselling, particularly as implantation may now be carried out soon after birth, before the parents have come to terms with the diagnosis.

With UNHS recently put in place in WA (Ear, Nose and Throat Advisory Group, 2011), the circumstances in which the accounts in this study were formed have changed. However, even in contexts where UNHS was already implemented (Hardonk et al., 2011), comments made by parents are similar to those of the current study: necessity of adequate support at diagnosis to minimise parental distress, dissatisfaction at the limited range of alternatives with regard to communication mode offered, the absence of information on aspects of deaf culture and communication through sign language, and the negative effect of the medically focused decision-making context on the parents' wellbeing. The current findings are timely and informative in WA in terms of employing appropriate and suitable care interventions and training programs in the necessary knowledge and competencies for professionals in the field.

The experiences of the participants highlight the need to be consistently reminded of the basics that so many professionals take for granted (Ben-Itzhak et al., 2005). A central message for professionals working in this area is realising the importance of honouring each parent's way of absorbing the information that their child is deaf, and taking the cue from them as to how to proceed in order to provide the appropriate, informed and unbiased support that will ultimately lead to a partnership and empowerment of families. Although the findings highlight earlier work on parental needs (Yucel, Derim, & Celik, 2008), a strength of this study is that it moves beyond one care event (Archbold et al., 2008; Fitzpatrick et al., 2007) and the early care of the child (Hardonk et al., 2011) to include insights from the life span of the child, from early schooling through the teens and into adulthood.

The study design has a number of limitations. Firstly, it is recognised in the literature that parents' stress responses and coping strategies to the impact of having a deaf child vary (Palfrey, Walker, Butler, & Singer, 1989; Punch & Kidd, 2001). Level of education and income levels may influence this (Pipp-Siegal, Sedey, & Yoshinaga-Itano, 2002). In this regard, a potential limitation of this study is that participants self-selected to participate. Therefore no effort was made to control level of education or socioeconomic status of parents. Only families who were proactive and had strong relations with the WA Deaf Society or WAIDE were included. In addition, self-selection may echo their identification with being parents of a deaf child, reflecting a preoccupation with this role. It is recognised that the findings of qualitative research cannot be generalised beyond the specific sample and setting; however, it is acknowledged that results may identify trends that may apply in similar situations (Creswell, 2007).

Second, it cannot be presumed that all parents' experiences of having a deaf child are equivalent. A number of extraneous variables that may impact include the age of the parents when the child was born, the cause of deafness, the birth order of the deaf child, number of children in the family, number of deaf children and presence of grandparents in the family, to name a few. These variables were not included as selection criteria for this study as the focus was on the general experience of hearing parents with deaf children. However, it cannot be assumed that these variables did not influence the ways in which the participants experienced their role. The mother of child A and B noted that once the

second child was diagnosed as deaf, she and her husband decided to become a 'deaf family', as she put it, enrolling themselves, their two hearing children and two deaf children in Auslan classes, and making a conscious decision to communicate in both sign and spoken language simultaneously in the home.

Third, the study design was based on parental perspectives on past events and thus involved reconstructing events, decisions and experiences as a consistent reality. Recall bias creeps into retrospective memory (Aldrovandi, 2009). Although a life-grid method was loosely applied to help minimise recall bias, this is certainly not foolproof (Berney & Blane, 1997; Blane, 1996).

Finally, an important component of qualitative research is the involvement of the researcher as part of the research process. Although reflexive rigour was ensured through an audit trail documenting the research process, a reflective diary and triangulation, and while direct quotations are included to enable the reader to assess the trustworthiness of the interpretations, the themes highlight the co-constructive nature of qualitative research and thus the findings of this study reflect one version of reality and may be interpreted differently by others (Smith, 2003).

The needs of a group of hearing parents of deaf children have been identified. From this research, it can be posited that how a hearing parent is informed of his or her child's deafness, how they are helped to understand deafness, the choices of communication and the emotional and informed support they receive may influence not only the life of their child, but their own health and that of their family.

This is an emerging era for deaf children in WA and with that arise new issues for their parents and for professionals in the area. The voices of the parents in this study can help inform these challenges and may help those involved to respond flexibly to the language, education, cognitive and social development of the child at all stages of life. Beyond language and education, issues of socialisation, emotional development and identity over the life span give ample opportunity for further investigation. As deaf children of deaf parents are found to be in line with the hearing child in terms of cognitive, social and communication development (Marschark & Spencer, 2010), these parents could potentially offer much to the hearing parents of deaf children. Further research combining the experiences of the deaf children who have hearing parents at various stages of life is needed to determine the full potential of the challenges of parenting a deaf child in a hearing world.

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