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Parental Involvement in the Care and Intervention of Children with Hearing Loss

Ennur Erbas^{a,b}, Nerina Scarinci^{a,b}, Louise Hickson^{a,b}, and Teresa Y.C. Ching^{b,c}

^aThe University of Queensland, Brisbane, Australia

^bThe HEARing Cooperative Research Centre, Melbourne, Australia

^cNational Acoustic Laboratories, Sydney, Australia

Abstract

Objective—The present study aimed to explore the nature of parental involvement in the intervention of children with hearing loss, as experienced by parents.

Design—A qualitative descriptive methodology was adopted to conduct semi-structured in-depth interviews with a purposive sample of parents who have a child with hearing loss.

Study Sample—Seventeen parents of 11 children aged 6 to 9 years participated in this study.

Results—The overarching theme of parents taking the central role was identified using thematic analysis. This overarching theme connected five themes which described the nature of parental involvement: (1) parents work behind the scenes; (2) parents act as ‘case managers’; (3) parents always have their child’s language development in mind; (4) parents’ role extends to advocacy for all children with hearing loss; and (5) parents serve a number of roles, but at the end of the day, they are parents.

Conclusions—The results indicate that parental involvement in the intervention of children with hearing loss is multifaceted in nature and incorporates a broad range of behaviours and practices. These findings have important implications for the provision of family-centred practices.

Keywords

children; hearing loss; parental involvement; intervention; family-centred practice

Recent estimates indicate there are 32 million children in the world with a hearing loss of mild or greater severity in the better ear (World Health Organization, 2013). In Australia, early intervention services are offered to children with hearing loss and their families from birth to school entry. Services are delivered through home visits, family visits to a centre, telepractice, or a combination of these three options. Families access services from a range of professionals such as ear, nose and throat specialists (ENTs), paediatricians, audiologists, speech pathologists, and occupational therapists. Formal schooling begins with a foundation year (e.g., kindergarten, preparatory year, and transition), followed by primary and

secondary school, which together run for 12 years (Department of Education and Training, 2015). In today's society, there is wide acceptance that parents can make the greatest difference to children's achievements (Harris & Goodall, 2008). Hence, parental involvement in the intervention of children with and without special needs is strongly encouraged.

Literature on children with hearing loss has indicated that active parental involvement can lead to desirable language (Moeller, 2000; Sarant et al, 2009, 2014; Yanbay et al, 2014) and reading skills (Calderon, 2000; Sarant et al, 2015). These findings were based on closed-ended measures, which were completed by clinicians and teachers. While the importance of parental involvement was emphasised in these studies, the authors provided a very limited description of how parents actually participated in their child's intervention. Thus, the operational use of parental involvement is unclear.

Desjardin (2003) highlighted that a more accurate understanding of involvement could be obtained by asking parents directly about their own perceptions. Jointly with a team of professionals at the House Ear Institute in California, the researcher designed a questionnaire comprised of three main sections: demographic information, self-efficacy, and parental involvement. The latter section has two subscales: (1) parental involvement of child amplification use; and (2) parental involvement of child's speech-language development. Using this tool, perceptions of self-efficacy and involvement were reported for 54 mothers receiving early intervention (Desjardin, 2005). Although, Desjardin aimed to collect maternal perceptions regarding these two constructs, the findings may not be entirely representative of the mothers in this study as the questionnaire was not developed directly from a parent perspective and the Likert-type scale may have restricted participant reports.

McNeil and Chabassol (1984) conducted research to examine parents' perspectives on this subject as well. However, in contrast to Desjardin (2005), their study explored the nature of paternal involvement in the intervention of children with hearing loss. Married couples, made up of 20 wives and their husbands were individually interviewed about the husband's (i.e. father's) feelings towards his child with hearing loss, whether he responded to his child's needs, and his degree of technical involvement. Indicators of technical involvement included fathers' attendance at meetings with specialists, frequency of participation in recreational activities with the child, and ability to use the child's preferred mode of communication. The parents in this study perceived fathers as being involved in their child's intervention, but agreed that paternal involvement was different to maternal involvement. While some open-ended questions were used to collect data in this study, the majority of questions were closed-ended ('yes-no') or followed a Likert-type format. The nature of paternal involvement, therefore, was essentially determined by the researchers who developed the questions themselves. It is important to ensure that more in-depth information is collected from participants by limiting the use of closed-ended questions, which may not allow for the full scope of the parents' perspective to be obtained.

More recently, Zaidman-Zait and Young (2008) used an action-project method to explore parental involvement in habilitation following cochlear implant surgery. Two mothers participated in the study: a mother of a 39 month old girl who had been implanted for a

duration of 18 months, and a mother of a 25 month old boy who had been implanted for a duration of 10 months. Both mothers believed that they played an important role in their child's intervention and sometimes acted as 'the teacher'. The mothers also expressed that they aimed to establish a healthy parent-child relationship by engaging in pleasurable interactions with their child. Advocacy on behalf of the child was another action that was described by the participants. Although, the findings of this study provide additional insight into the nature of parental involvement, they were based on only two cases and other relevant actions are likely to be identified with a larger sample of participants.

Bruin and Ohna (2015) also undertook qualitative research to collect data on parents of children with cochlear implants. Ten mothers and four fathers of implanted children ranging in age from 3 to 11 years were interviewed about their experiences after the surgery. This Norwegian study specifically explored how parents responded to the uncertainty regarding their child's development and what professional support meant to them. Two narratives were identified from the interview data: the parent as learner and the parent as teacher. The parents valued information as gaining knowledge helped them to support their implanted child. All parents described consciously incorporating structured and unstructured activities directed towards spoken language skills into family life, because they felt responsible for their child's future outcomes.

In summary, there is some research that provides parents' perspectives on the nature of parental involvement. Nevertheless, literature in this area is scarce. To date, the studies that were conducted predominantly used closed-ended questions to collect data (Desjardin, 2005; McNeil & Chabassol, 1984) or used open-ended questions but only included parents of children with cochlear implants (e.g., Bruin & Ohna, 2015; Zaidman-Zait & Young, 2008). Since the innovation of cochlear implantation, a vast amount of paediatric research has focussed on the impact of this intervention (Thoutenhoofd et al, 2005). In order to support all families of children with hearing loss, there is a need for research that also includes parents of children with hearing aids. As parents play a huge role in their child's life, it is vital to examine the impact they may have on the outcomes of children with hearing loss. However, to successfully carry out this research, it is important to first clarify how parents are involved in their child's intervention. The present study aimed to expand on previous research by exploring the nature of parental involvement in the intervention of children with hearing aids and children with cochlear implants. This study sought to provide a deeper understanding of parental involvement through the use of a qualitative research methodology.

Methods

Research Strategy

A qualitative descriptive methodology was adopted to explore the nature of parental involvement in the intervention of children with hearing loss. Qualitative description is an approach that aims to offer "a comprehensive summary of events in everyday terms" (Sandelowski, 2000, p.334). It is based on a naturalistic paradigm whereby there is no predetermination of variables and research is carried out in the natural setting (Lincoln & Guba, 1985). The present study had some phenomenological undertones because it

investigated parent experiences. Phenomenology is a theoretical perspective, which involves understanding the ‘lived experience’ of social phenomena as described by individuals in the sample (Patton, 2002).

Context of the Present Study

Participants of this study were parents of children in the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study (Ching et al, 2013). The LOCHI study was designed to examine the speech, language, academic, psychosocial, and functional outcomes in a population-based cohort of Australian children with permanent hearing loss. All families residing in the Australian states of New South Wales, Victoria, and Southern Queensland were invited to participate in the prospective LOCHI study if their child with hearing loss: (1) was born between 2002 and 2007; and (2) accessed services at an Australian Hearing centre before their third birthday. Australian Hearing is the national service provider for children, adolescents, and young adults with hearing loss. There are 451 children enrolled in the LOCHI study.

Sampling

Parents were eligible for this substudy if their child had a nonverbal cognitive ability score of ≥ 85 (Wechsler Non Verbal Scale of Ability; Wechsler & Naglieri, 2006) and had received educational intervention over the past 3 years. A letter of invitation, information statement, and expression of interest form was sent to 224 eligible families with a reply-paid envelope. Upon receiving expressions of interest, LOCHI researchers phoned individual families to provide further details about the study. Fifty-one families expressed an interest in participation. The first 10 families who provided informed consent Of those who expressed interest, parents from 10 families were recruited for this substudy using maximum variation sampling to encompass heterogeneity in the sample and obtain information-rich cases. Maximum variation sampling is a type of purposive sampling that is designed to offer diverse perspectives and capture common patterns that are shared among the cases explored (Patton, 2002). In this study, variation was sought for parents in terms of type of communication approach used with the child, cultural background, child’s degree of hearing loss, and child’s language outcomes.

Participants

Seventeen parents from 10 families were recruited for the present study. Other researchers in this field have reported reaching saturation after collecting qualitative data from a similar number of parents (Fitzpatrick et al, 2008). Five families lived in Victoria, four in Queensland, and one family lived in regional New South Wales. With the exception of one mother who was from a blended family, all parents were from nuclear families. At the time of data collection, there were two or more children living in each household. One family identified themselves as Deaf and used Australian Sign Language (Auslan) to communicate. Two parents migrated to Australia from Turkey as adults and had limited English language skills. The 10 families accessed a range of centre-based, home-based, and telepractice services including medical, audiology, physiotherapy, occupational therapy, and speech pathology. They had received early intervention from programs that followed an auditory-

verbal therapy, auditory-oral, total communication, or a bilingual-bicultural approach. A summary of the participant characteristics are presented in Table 1.

Data Collection

Approval for this study was granted by the Behavioural and Social Sciences Ethical Review Committee of The University of Queensland and the Human Research Ethics Committee of Australian Hearing. Before commencing data collection, both verbal and written informed consent was obtained from participants. The first author¹ (EE) conducted a semi-structured in-depth interview with each participant at their homes ($n = 14$) or by telephone ($n = 3$). Each parent was interviewed individually, except for three couples who preferred to be interviewed together. In these three face-to-face interviews, both the mothers and fathers actively contributed to the conversation. At the time of the interviews, the first author was blinded to the: (1) demographic characteristics of participants; (2) demographic characteristics of the children with hearing loss; and (3) outcome data of the children with hearing loss to minimize any potential interviewer biases. The data collection for parents in this study occurred from February 2013 to December 2013.

In-depth interviewing allowed participants to talk openly about their experiences in their own words (Minichiello et al, 1995). A guide was developed to ensure that questions related to the research aims were covered in all interviews. The use of an interview guide ensured consistency across the conversations. The guide comprised of open-ended questions that were adapted for each participant based on the flow of the interview. Participants were sent a list of stimulus questions before their interview to encourage self-reflection and help them gain more insight about the study (Patton, 2002). The interviews were conducted in: (1) spoken English with 13 parents; (2) spoken Turkish with two parents, then subsequently translated into English by the first author who took care to preserve cultural meanings and remain as close to the original text as possible; and (3) spoken English, which was communicated by an accredited Auslan interpreter with two parents. The Auslan interpreter had previously worked with the signing family and was requested by them. During the interview, the interpreter also translated the parents' signed responses into English. All interviews were audio-recorded, except the interview with the signing parents which was video-recorded. The duration of interviews ranged from 30 to 171 minutes ($M = 84.79$ minutes; $SD = 37.95$ minutes).

Analysis

The interviews were transcribed verbatim and transcripts were checked against the recordings for accuracy. Following the proofing process, transcripts were de-identified and thematic analysis was undertaken according to the step-by-step guide by Braun and Clarke (2006). As there is limited literature on the nature of parental involvement in the intervention of children with hearing loss, the data were analysed in an inductive way. The inductive

¹The first author grew up as an English/Turkish bilingual and is a native user of both languages. She was previously employed as an audiologist at Australian Hearing. Participants were informed that this research study was a part of the first author's PhD. They were also informed that she was an audiologist as each participant asked about her profession. However, her previous employment at Australian Hearing was not disclosed to participants to ensure that they felt comfortable to be open and honest without hesitation that their responses may have an influence on the provision of services from Australian Hearing.

approach involves identifying patterns and meanings without a preexisting theory, hypothesis, or coding frame (Braun & Clarke, 2006; Patton, 2002). During the initial phase of analysis, the first author read each transcript at least twice to become familiar with the data. Initial ideas about the questions under study were noted in a memo book and consulted later when generating codes. Coding was carried out by organising small sections of the transcripts into meaningful groups related to the research topic. These groups or codes were then examined for common patterns and differences, leading to the identification of potential themes. The themes included categories and subcategories reflecting parents' experiences of involvement in their child's intervention. Coded data extracts were reviewed and all transcripts were re-read in entirety to check that the identified themes appropriately represented the interview data. Throughout this process, themes were refined and subsequently all transcripts were re-coded using the revised coding frame. Revision of themes was completed when it was recognised that the set of categories matched the data well. The analysis was a continuous and iterative process that involved moving back and forth through the different phases. Interview data were organised and managed electronically using the NVivo 10 (QSR International) software program.

Rigour

Triangulation with information from different sources, peer reviews, and member checking was used to ensure reliability of the findings. To enhance trustworthiness of the data collected, some of the same questions were asked of mothers and fathers in seven of the 10 families where both parents participated. An examination of these data revealed consistency between the two sources in the seven families. Furthermore, the findings were reviewed at several phases of the analysis by the second and third authors (NS and LH). Research meetings were held where discussions occurred and categories/themes were reorganised and refined in line with the consensus reached by the team. The investigators acknowledged their backgrounds as allied health professionals and examined data in the context of this potential bias. Following completion of the data analysis, participants were sent a written summary of the main findings and asked to provide feedback. Responses were received from 15 of the 17 participants who supported the investigators' interpretation of their experiences regarding the nature of parental involvement.

Results

The results indicated that parental involvement in the intervention of children with hearing loss is multifaceted in nature and incorporates a broad range of behaviours and practices. The overarching theme of 'parents taking the central role' was identified as a key link between and across five themes which described the nature of parental involvement: (1) parents work behind the scenes; (2) parents act as 'case managers'; (3) parents always have their child's language development in mind; (4) parents' role extends to advocacy for all children with hearing loss; and (5) parents serve a number of roles, but at the end of the day, they are parents. An example participant quote representing each of the categories and subcategories within the five themes is presented in Tables 2 to 6. All identifiers such as names and place of residence are pseudonyms.

Overarching Theme: Parents Take the Central Role

The overarching theme of parents taking the central role was reflected in the five themes identified. This theme was a key element to parents being involved in their child's intervention. The parents expressed feeling responsible for supporting their child with hearing loss to maximise his or her potential. This finding was common across the sample regardless of participants' education level, cultural background, type of communication approach they adopted, and whether their child was fitted with hearing aids or cochlear implants. Furthermore, parents in this study were positive and had great expectations for their child's future achievements. They did not believe their child would achieve successful outcomes by simply attending appointments and going to school. Consequently, they took an active stance towards the intervention of their child with hearing loss. The following example is 1 of 28 quotes that illustrate this overarching theme: "I just think it's all up to the parents. You can't be expecting external sources to do everything for the child. They're not there all the time, it's you with the child" (Claire).

Theme 1: Parents Work Behind the Scenes

Theme 1 represents the aspects of parental involvement, which cannot be observed by professionals during appointments and meetings. The categories and subcategories incorporated in this theme are listed in Table 2. Here, parental involvement can be thought of as similar to the making of a movie in that a tremendous amount of work goes on behind the scenes yet the audience only sees the final product. Similarly, professionals observe children with hearing loss and their families in a short appointment timeframe and may not be aware of how parents are involved in their child's intervention in their day to day lives. Parents in this study described various ways in which they tried to ensure optimal conditions for their child's habilitation 'behind the scenes'. For example, one mother spoke about how she and her partner designed their home, as well as implemented other strategies to reduce background noise:

In designing the house... we knew that this space, having a big open space with lots of glass is always problematic acoustically, so we put the acoustic plasterboard in on the ceiling just to absorb some of the soundwaves so there's not as much reverberation, and also the texture in the ceiling, just not having a plain flat ceiling. We've done things like put the washing machine in a cupboard just to reduce the noise of the washing machine. (Laura)

Parents commented on working together with their partners to provide intervention for their child with hearing loss: "We both work but we're not well off. We don't have a lot of money and all our money goes to our children to continue their access to the hearing world and help them develop skills" (Sophie). Many parents in the sample described the father's key role as emotionally and financially supporting the mother so that she is able to continue her habilitation efforts: "You can only work with the father up to a certain point, because I have to earn money, I have to go to work. It's important that the mother is strong... I always supported Sabiha but she did the work" (Adam).

Finally, almost all of the parents discussed their efforts to gain knowledge about hearing loss and related subjects by actively doing research, participating in informational events, and

pursuing independent learning. One participant said "... we also did heaps and heaps of research like on the net... I just read to interpret and understand how much hearing loss and what that actually meant" (Thomas). It was evident from the interviews that parents felt they could support their child's development more effectively by being well informed.

Theme 2: Parents Act as 'Case Managers'

During the interviews, participants described a range of actions they engaged in to ensure that their child with hearing loss can access services and resources that will help him or her achieve desirable outcomes. These are listed in Table 3. Just as case managers provide an array of personalised services to individuals with complex needs, so do parents to offer the best possible intervention for their child with hearing loss. This domain of parental involvement includes arranging and attending appointments/meetings, evaluating services, communicating with various professionals, educating others, advocating on behalf of the child, and empowering the child to self-manage his or her hearing loss.

Theme 3: Parents Always have their Child's Language Development in Mind

Participants gave many examples of how they supported their child's language development (Table 4). It was apparent from these examples that the parents' primary intervention goal was to help their child with hearing loss acquire proficient language skills. One father articulated that he wanted his son to integrate into the mainstream society: "To make him fit into the hearing speaking world... to have a child where the world didn't have to adapt to him, where he actually adapted to the world around him" (Hugh). Therefore, with such goals in mind, parents: (1) made significant lifestyle changes; (2) consciously incorporated interactive activities such as reading, telling stories, singing, talking, signing, and playing with the child into their everyday lives; (3) carried communication therapy over to the home; and (4) encouraged their child with hearing loss to use communication strategies. While parents generally spoke positively about these experiences, many reflected on the intensity of their role. One mother commented that her involvement in teaching and carrying therapy over to the home caused her distress as these practices were not a natural part of parenting:

The sitting there for eight months going 'sss' for snake until 8 or 10 months later you got 'sss' as a sound... I don't know, I think it's, so the teacher part is all the stuff that's not natural. The teacher stuff was all the stuff beyond what a normal parent does with their kid. It's beyond the one or two books you might sit down with a child a day to try and immerse them in reading. With trying to go, "No, if I don't do 20 books today then I haven't done my job as a mother to Sam".
(Christine)

Theme 4: Parents' Role Extends to Advocacy for all Children with Hearing Loss

Conversations with the participants indicated that a parent's role extends beyond their own child's intervention such that he or she becomes an advocate for all children with hearing loss. This fourth theme has three categories that are presented in Table 5. Parents spoke about their involvement in the education and support of families, role of advocacy for all children with hearing loss, and interactions with other hearing impaired children and their

family members. There was a strong sense of parents wanting to improve services, and to support and connect with others who are in the same circumstance as themselves.

Theme 5: Parents Serve a Number of Roles, but at the End of the Day, They are Parents

While parents discussed a number of roles that they took on, such as audiologist (as described in theme 1), case manager (theme 2), speech pathologist (theme 3), teacher (theme 3), and philanthropist (theme 4), they also reported that in many ways their involvement is no different to what it would be for a child with normal hearing. Many parents described behaviours that they would display and actions they would perform regardless of whether their child had a hearing loss or not. These are summarised in Table 6. In relation to this theme, it appeared that the fathers in the sample took on the role of the 'everyday parent' more so than the mothers. One parent said:

I know for Julia it was probably tougher than myself, because I'd go off to work, I was doing that, going to work, coming home. Julia was doing all the other work during the day. I'd help wherever I could be involved, but to me it was just who he is and I never saw it as any different. (Ian)

Discussion

It is widely accepted that parental involvement is a factor that contributes to positive intervention outcomes in children with hearing loss. However, the operational meaning of parental involvement is unclear and research that explores the nature of this construct is limited. The present study complements the findings of previous research (Bruin & Ohna, 2015; Desjardin, 2005; McNeil & Chabassol, 1984; Zaidman-Zait & Young, 2008) and provides a deeper understanding of parental involvement by exploring the experiences of 17 adults who parent a child with hearing loss. Although the participants in this study offered diverse perspectives, five common domains of parental involvement were shared among them: (1) parents work behind the scenes; (2) parents act as 'case managers'; (3) parents always have their child's language development in mind; (4) parents' role extends to advocacy for all children with hearing loss; and (5) parents serve a number of roles, but at the end of the day, they are parents. These five domains were connected by an overarching theme of parents taking the central role. This theme highlighted that parents wanted the best for their child, which led them to actively participate in his or her intervention.

Participants in this study spoke about how they engaged in a wide range of behaviours and parenting practices to support their child with hearing loss. While some of these categories of parental involvement were described in the current literature on children with hearing loss, many were not previously identified (e.g., making an effort to create optimum conditions for appointments). The construct of parental involvement has been commonly conceptualised as being unidimensional or bidimensional. This is possibly because previous research was generally conducted from the expert's perspective of parental involvement. From an expert's perspective, indicators of parental involvement include: attending appointments, meetings or school related functions, providing input into the child's IEP plan, participating in therapy sessions, advocating on behalf of the child, and following through with the advice received from professionals (Calderon, 2000; Desjardin, 2005;

Moeller, 2000). The present study demonstrates that parental involvement in the intervention of children with hearing loss is much more extensive than what has been operationalised in earlier work. Furthermore, in contrast to previous research (Calderon, 2000; Desjardin, 2005; Moeller, 2000), this study did not separate parental involvement into the early intervention and school education contexts because the identified themes and categories overlapped between the two. The data reported in this paper were collected from parents of children who were attending primary school and had received early intervention. Given that the nature of parental involvement changes over time, some of the categories identified in this study may not be applicable to parents of older children. Thus, it is hoped that these preliminary findings will encourage further research with older age groups. Greater insight into parental involvement can assist researchers to develop an objective measure of this construct. The development of a parental involvement measure with psychometric properties would allow future studies to investigate the relationship between various domains of parental involvement and child outcomes. A deeper understanding of parental involvement can also help professionals to promote participation in these different domains and support parents' efforts of involvement.

Although this study was not designed to compare maternal involvement to paternal involvement, many similarities and differences were evident between the mothers and the fathers who were interviewed. Similar to the mothers, the fathers participated in all the different domains of parental involvement that were identified. However, the fathers generally took on the role of the breadwinner and were working full-time. The mothers took on "the lion's share" of attending appointments, communicating with various stakeholders, managing hearing devices, and carrying therapy over to the home. This is consistent with the findings reported over 30 years ago by McNeil and Chabassol (1984). In the present study, the mothers were the ones who tended to make significant lifestyle changes such as resigning from their jobs. Nevertheless, the fathers were involved in their child's intervention and the mothers valued their contributions. A major aspect of paternal involvement was providing financial and emotional support to the mother, as well as assisting in household tasks and other errands so that she was able to continue performing her role as the primary caregiver.

Social resources such as support from the partner have been reported as helping families to cope with stress that is associated with raising a hearing impaired child (Hintermair, 2000). Literature also indicates that this variable is related to perceived life satisfaction (Lederberg & Golbach, 2002; Pipp-Siegel et al, 2002). Therefore, family therapy should be considered as a component of the intervention program, particularly for mothers who feel dissatisfied with the support they receive from their partners (Lederberg & Golbach, 2002). In addition to reducing stress levels, therapy directed at enhancing family relationships may lead to improved child outcomes, as research has demonstrated a significant correlation between satisfaction with social support and positive parent-child interactions (Meadow-Orlans & Steinberg, 1993). It is essential for professionals to consider family systems, emotional experiences of family members, and the availability of support networks. While a family-centred approach is recognised as the ideal model of service-delivery, many experts working with hearing impaired children and their families may not have the resources or skills to

implement such practices (Roush et al, 1991; Roush et al, 1992). Further research examining clinical practices and professionals' ability to support families is warranted.

A finding that was unique to this study is that many participants described behaviours and parenting practices that they adopted, which were not necessarily related to their child's hearing loss. They made comments such as "but that's no different from what we do with Matthew [child with normal hearing] or anyone else" (Thomas). Categories that were incorporated in this theme include showing affection to the child, being responsive to the child, involving the child in daily or weekly routines/chores, encouraging the child to try new things, supporting the child to develop new skills, helping the child with school work, and participating in school activities. An interesting finding in relation to this theme was that the fathers in the sample appeared to take on the role of the 'everyday' parent more so than the mothers.

Similar to the findings of previous research (Bruin & Ohna, 2015; Zaidman-Zait & Young, 2008), the parents in the current study, especially the mothers, felt responsible for their child's outcomes and took on the role of 'teacher'. They also described acting as the audiologist, case manager, speech pathologist, and philanthropist. These findings have important implications for the provision of family-centred practices. Primarily, it is important that service providers acknowledge the many roles that parents take on and ensure that they have the support to fulfil these roles. Furthermore, given that parents hold themselves accountable for their child's outcomes, intervention programs should offer counselling services to reduce the risk of parents experiencing negative emotions such as guilt and unhappiness if their child achieves poor outcomes. Certainly, these negative emotions may be experienced in parents of children with hearing loss as described by one mother in the present study: "I felt like a failure as a mum, as a teacher or whatever because he didn't learn and progress... At the time, I hated myself... I thought I was a terrible, terrible mum... I really felt awful" (Christine). While service providers are advised to promote parental involvement, the parent-child relationship should not be reduced to a pedagogical intervention (Suisa, 2006). Primary caregivers may require assurance that it is okay to be an 'everyday' parent. Affection, responsiveness, and positive parent-child interactions have been associated with better cognitive and language outcomes in children with established developmental delays and children at risk for developmental problems (Innocenti et al, 2013). Intervention programs focus on enhancing certain parenting skills (e.g., knowledge of hearing loss and following a communication approach). Although these are important and necessary, intervention of children should also incorporate a focus on general parenting, because mediating models suggest that enhancing such parenting skills will lead to greater improvements in children's outcomes (Innocenti et al., 2013).

As reported above, the parents of this study spoke about experiences that are common to children with normal hearing. Nevertheless, their perceptions of parental involvement may differ from those of other parents. Parents of children with typical development are also involved in their child's learning (e.g., Evans et al, 2000; Sénéchal et al, 1998), however, they may think differently about the importance of academic development in young children. Research has demonstrated that parents with high levels of education/literacy skills are likely to believe children should develop basic reading and maths skills in the natural setting

without the use of formal teaching activities (Fitzgerald et al, 1991; Stipek et al, 1992). Regardless of education level, many of the parents interviewed in this study expressed that they consciously engaged in teaching activities and formal therapy to support their child's language development. It is hypothesised that parents of children with hearing loss may feel more pressure to be involved in their child's language development and use didactic teaching approaches as compared to parents of children with normal hearing; further research is required to explore this hypothesis.

In regards to supporting families of children with hearing loss, in the present study, parents of children with different hearing technologies reported similar experiences of involvement in intervention. This finding highlights that parents of children with hearing aids require as much support and attention as parents of children with cochlear implants. The current literature is unbalanced in that it is inclined towards families of children with cochlear implants. In order to provide adequate and high quality support to all families, it is important that research not only targets families of children with cochlear implants, but also includes those of children with hearing aids, unilateral losses, and conductive losses.

A possible limitation of this study was that some of the data collected relied on parents' retrospective accounts of their involvement. Parents were asked to describe how they are currently involved in their child's intervention and how they were involved in the past. This was positive in that it allowed parents to reflect on their experiences, but there is a possibility that they might have provided different responses had they been interviewed at the time when the events were actually taking place. Another potential limitation may be that all the parents who volunteered to participate in the interviews appeared to be actively involved in their child's intervention. One may argue that these results are not transferable to parents who are not as involved in their child's intervention. However, as the aim of the research was to explore the many ways that parents are involved in their child's intervention, this may be considered a strength, because it would allow the identification of a more complete picture of how parents participate in their child's learning and development. Lastly, there is need for more discussion on how to provide purposeful support to families of children with hearing loss in the most optimal way. In addition to exploring the nature of parental involvement, this study explored factors that influence parents' involvement practices, as perceived/ experienced by parents and professionals. Numerous facilitators and barriers to the intervention of children with hearing loss were identified and will be reported in a forthcoming publication.

Despite the limitations, this study offers a broader and deeper understanding of the nature of parental involvement for children with hearing loss than what has been previously conceptualised. Participants in this study demonstrated that parental involvement is multifaceted in nature. While these findings offer much needed insight into the construct of parental involvement, further research on this subject is warranted. A greater understanding of how parents are involved in their child's intervention will ultimately lead to the development of more family-centred approaches to intervention that acknowledges the central role of the family in the whole process. As one parent said, "we have to make [intervention] work so these kids can be more successful..." (Arthur).

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Abbreviations

Auslan	Australian Sign Language
ENT	Ear, Nose, and Throat specialist
IEP	Individualised Educational Plan
LOCHI	Longitudinal Outcomes of Children with Hearing Impairment

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Table 1

Participant characteristics

Family ID.	Language used at home	Participant group	Pseudonym	Age (years)	Gender	Education	Degree of hearing loss	Hearing device(s)	Age at diagnosis	Age at device fitting
1	Turkish	Parent	Sabiha	34	Female	High school	-	-	-	-
		Parent	Adam	35	Male	High school	-	-	-	-
2	English	LOCHI child	Laila	7	Female	Grade 2	Profound	Bilateral HA	2 months	9 months
		Parent	Stacie	41	Female	University	-	-	-	-
		Parent	Thomas	43	Male	University	-	-	-	-
3	English	LOCHI child	Nathan	9	Male	Grade 4	Moderate	Bilateral HA	24 months	25 months
		Parent	Christine	36	Female	University	-	-	-	-
4	English	LOCHI child	Sam	8	Male	Grade 3	Profound	Bilateral CI	10 months	17 months
		Parent	Claire	43	Female	High school	-	-	-	-
		Parent	Shaun	44	Male	High school	Moderate to severe [§]	Bilateral HA	9 years	42 years
5	English	LOCHI child	Luke	8	Male	Grade 3	Moderate	Bilateral HA	17 months	18 months
		Parent	Laura	41	Female	University	-	-	-	-
		Parent	Alain	45	Male	University	-	-	-	-
6	Auslan	LOCHI child	Mia	7	Female	Grade 2	Profound	Bilateral CI	15 months	20 months
		Parent	Sophie	43	Female	High school	Profound	Monaural HA	18 months	24 months
		Parent	Arthur	42	Male	High school	Severe	Unaided	36 months	-
		LOCHI child [#]	Kierra	7	Female	Grade 2	Profound	Bilateral CI	1 month	8 months
		LOCHI child [#]	Paxton	9	Male	Grade 3	Moderate	Bilateral HA	2 months	4 months
7	English	Parent	Hannah	40	Female	University	-	-	-	-
		LOCHI child [#]	Ella	7	Female	Grade 1	Profound	Bilateral CI	1 month	14 months
8	English	Parent	Candice	44	Female	University	-	-	-	-
		Parent	Hugh	44	Male	University	-	-	-	-
9	English	LOCHI child	Ethan	7	Male	Grade 2	Profound	Bilateral CI	1 month	10 months
		Parent	Julia	45	Female	High school	-	-	-	-
		Parent	Ian	50	Male	High school	-	-	-	-
10	English	LOCHI child [#]	Oliver	8	Male	Grade 3	Mild	Unaided [*]	3 months	2 years
		Parent	Eryn	34	Female	University	-	-	-	-

Family I.D.	Language used at home	Participant group	Pseudonym	Age (years)	Gender	Education	Degree of hearing loss	Hearing device(s)	Age at diagnosis	Age at device fitting [♣]
		LOCHI child#	Benjamin	6	Male	Grade 1	Profound	Bilateral CI	1 month	5 months

Note. Auslan = Australian sign language; CI = cochlear implant; HA = hearing aid.

[♣]For children with hearing aids, this is the age at their initial hearing aid fitting. For children who underwent cochlear implantation, this is the age at cochlear implant switch-on.

[§]This parent's hearing loss is due to mastoiditis.

^{*}While this child used to wear bilateral hearing aids at 5 years of age, he is currently unaided.

[#]Five of the 11 children (45.45%) have a disability in addition to hearing loss. This proportion is consistent with the prevalence rate of approximately 40% for children with hearing loss and additional special needs (Picard, 2004). The disabilities are autism spectrum disorder, mild vision loss, developmental delay with auditory neuropathy, dysmorphic thumbs, dyspraxia, and Waardenburg-Shah syndrome.

Table 2

Theme 1: Parents work behind the scenes

Category	Subcategory	Example participant quote
Tries to create optimal conditions for habilitation and learning	Makes an effort to create optimum conditions for appointments	<i>The important thing for us was to present our daughter in the optimum way to try and achieve the optimum outcome of whatever appointment she was going to. So that means her having a good sleep the night before, having a good walk... Making sure she had something to eat...</i>
	Tries to create optimal conditions at home, in the car, and when out and about	<i>Like we turned off the radio and the TV and we were really vigilant about that.</i>
	Assists teachers and staff members to ensure the educational setting is an optimal acoustic environment	<i>I went and met the teacher... and I like took in the rubber matting and said "you need to put this under the cups of pencils and all things that are going to bang".</i>
	Helps the child adapt to hearing technology and manages the use and maintenance of devices	<i>I spent just the entire day just sticking these things back in her ear, then the next day sticking them back in her ear... and she gave up. So that was great, she left them in.</i>
Parents work together so the primary caregiver has the support they need to provide habilitation	Helps with housework and other errands	<i>I will do the cooking 90% of the time and therefore she is more involved in language after school than what I am those more energetic Monday, Tuesday, Wednesday days.</i>
	Provides emotional support	<i>In the early days... she was very sad. I always tried to make her feel better. I tried to support her as much as I could.</i>
	Provides financial support	<i>He was happy for me not to go to work, so he'd go to work... He was happy for me to step back from that and focus on the baby.</i>
Actively does research and learns new things	Actively does research to learn about hearing loss and related subjects	<i>In terms of my research, yes, I questioned everything and then looked for "Is this the best answer?"</i>
	Participates in courses, activities, conferences, seminars, and information nights	<i>I learnt about CI 2007 [conference] which was specifically looking at a bilateral implantation and auditory neuropathy... So I just immersed myself in that for five days.</i>
	Makes an effort to learn sign language	<i>So Shaun and I learnt [sign language]. We got a student who came and taught us for a while.</i>

Table 3

Theme 2: Parents act as ‘case managers’

Category	Subcategory	Example participant quote
Thinks ahead, plans, and implements plan to meet goals		<i>So like we see the ENT at Easter and go to the GP to get the speech therapy letter so that then we can get Ethan seen in like that part of the year. So you've sort of got to think a fair way ahead as well to be able to get those things to happen...</i>
If unable to carry out therapy over to the home or unable to help with schoolwork, parent organises for someone else to assist their child		<i>They have homework to do when they come from school. Because my English is limited I can't easily help them out. We used to struggle a little, but now it's better because we ask for support from people around us who speak English well.</i>
Books appointments and meetings		<i>So straight away then I contacted [the cochlear implant centre] and we set up appointments there.</i>
Attends appointments, meetings, and home-visit sessions		<i>Every two weeks we'd have a one-on-one session with the teacher of the deaf. Sometimes she'd come to us.</i>
Participates in the therapy during sessions and participates in keeping the child engaged in audiology appointments		<i>With all the mapping appointments there was definitely an involvement, you were expected to be involved to try to have that child as engaged with the sound as possible and only indicating the sounds that they really have heard.</i>
Evaluates the information received or the practices observed in appointments		<i>I would say "when do I do these things?" and Emma [teacher of the deaf] would always say to me "at every opportunity". I'd think about that and what that does mean?</i>
Communicates with multiple stakeholders so the child receives the most appropriate intervention	Asks professionals questions	<i>We always had a list of questions that we went in with that we had written down because we knew we'd forget something. So we always used to have like the notepad on the table to think of "Right, we need to ask them next week about this or that".</i>
	Gives feedback to professionals about their therapy and assessment plans	<i>I said "I think it's too hard, she just can't do it or she's not interested in it, can we try a different way?" So Chloe would incorporate that into her goals.</i>
	Participates in decision making for Individualised Educational Plan (IEP) goals at school	<i>We do quarterly meetings, support group meetings at the school... So we sit down and talk about Mia and her goals and agree on a set of goals for the semester...</i>
	Communicates with others about concerns, issues, and child's progress	<i>Sometimes she does not hear but because she feels embarrassed, she won't ask her teacher to repeat. I told her teacher about this in our meeting...</i>
	Educates others about the child's hearing loss, needs, and hearing technology	<i>So educating teachers every year is a big thing... it's up to the parents to go in and organise interviews or appointments before school starts and give them a heads up with managing somebody with hearing impairment.</i>
Advocates on behalf of the child	Passes on information between stakeholders	<i>She'd [the speech pathologist] just give me the exercises to do at home similar to what we were getting from the early intervention centre, and then I'd take them to the early intervention centre and then they'd work out the program.</i>
		<i>The first thing I did this year when I met his new teacher before the school year started was walked in and said, "This is the spelling book from last year, this is the word that somebody's read out to him to spell and this is what he wrote". So they say something like "sunburn" and he spelt suburb. They keep testing him in a normal spelling environment and now it's that whole forcing the point and making sure that they say the word... and at least give him the opportunity to say the word back and then do it...</i>
Encourages the child to be independent and proactive		<i>The thing that we've emphasised and I try to emphasise with him is that it's more about attitudes and values, that that's what's going to make him a</i>

Category	Subcategory	Example participant quote
so that they can manage themselves at school and beyond school		<i>success in life... whether it's managing his hearing aids, whether it's volunteering to go in the musical or volunteering for the junior leadership or any of those things and hoping that if he's able to do all that he'll be set up to look after himself.</i>

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Table 4

Theme 3: Parents always have their child's language development in mind

Category	Subcategory	Example parent quote
Dedicates their life to helping the child achieve successful communication outcomes	Moves to another suburb, state, or country	<i>Then we shifted to Hamilton when Ella, I think, was about two-and-half... we sold our house and shifted to be able to access the services at [the oral intervention centre].</i>
	Gives up work or reduces workload	<i>I had been working but I had to stop because I just had to focus on Mia. I was so totally kind of focused on her wellbeing that everything else kind of just left out the window.</i>
	Spends less time with friends and less time on leisure activities	<i>I didn't see very many of my friends, and leisure stuff or things like that... I didn't want to look back and have regrets and think if I wasn't having coffee with Jane once a week then I would have got further with Ethan. So I tried as much as I could to just really focus on him and to deliberately let other things slide.</i>
Does not give up on their child despite the negative outlook/feedback they received from professionals		<i>They said he needed to repeat prep and I found that really hard to swallow as well because I saw that he had it in him... I was like "no, he's trying now. He's getting there and I know he can make it". I quit work and we did the school in [the early childhood development program].</i>
Consciously incorporates interactive activities into everyday life to facilitate language development		<i>Everything I found was like we have to play this because it's educational and you'll learn how to do this if I play this game with you or this is our topic for the week so I'm going to find everything I can about this and plaster it around.</i>
Carries therapy over to the home		<i>She used to leave the toy that she brought along with her. And we would play and work with it until our next session. Then we would give it back to Heather and she would leave us a different toy or activity.</i>
Encourages the child to use communication strategies		<i>Communicating with the boys to make sure that they fully understand too where if they're in a group of people, where they need to be. "You've got to be in front of the group". Our involvement would be to encourage them to do that.</i>

Table 5

Theme 4: Parents' role extends to advocacy for all children with hearing loss

Category	Subcategory	Example parent quote
Gives back to help others and improve services/products	Contributes to education and support of other families of children with hearing loss	<i>Actually Dianne [early intervention manager] asked me to write about my experiences with Luke being diagnosed and they put that into some book that they handed out to parents of the children who were newly diagnosed.</i>
	Participates in research to improve products and services	<i>I was explaining to these guys tonight, we've got our teams and it's really important that we sit and we partake with the research side of things because your research comes to conclusive findings, your conclusive findings are what they use to fight with the government to say "we need more funding, we need you to provide this resource and this is how it works"...</i>
Advocates for all children with hearing loss		<i>I'm a big advocate for deaf children. I strongly believe that every deaf child should have the opportunity to speak and to sign.</i>
Networks with other families of children with hearing loss		<i>I've got another friend [mother of a child with hearing loss] who's really good at finding out the latest things and she and I just keep sharing information and resources and technology kind of things.</i>

Table 6

Theme 5: Parents serve a number of roles, but at the end of the day, they are parents

Category	Subcategory	Example parent quote
Shows affection to the child and is responsive to the child's needs	Shows affection to the child	<i>I would tell her that I loved her and make eye contact with her, put little toys in front of her and show her leaves if we went on a walk, put her in the pram.</i>
	Aware of the child's emotional well-being	<i>She has trouble with some sounds. For instance, in Turkish sometimes she says "deldim [geldim], dittim [gittim]" ... I try at home to teach her the correct way. I say "honey it's not duzel it's güzel". But I don't correct her in front of others because I don't want to hurt her.</i>
	Provides the child's basic needs	<i>Naturally you're his mum. So, you're there to cuddle, kiss... the normal stuff, the cuddles, the kisses, the food, the care, nurturing, mothering.</i>
	Is interested in what's happening with the child	<i>I'll ask questions about their friends and who they're mixing with so I've got an idea of the kids they're mixing with and all that kind of thing.</i>
	Spends time with the child doing things he or she likes	<i>In the afternoon sometimes we'll go for another swim. And in the evenings we might get some pizza or make some dinner. Something that excites them.</i>
Involves the child in daily or weekly routines and chores		<i>We invite both of them to be involved in the cooking... if we're gardening or doing things like that we very much try and involve them in those things.</i>
Encourages or supports the child to explore new things and develop skills	Encourages the child to try new things	<i>Nathan has grown into a little boy who's willing to try most things now. When he was younger he seemed a little bit more timid but I think our encouragement that he give everything a go whether he likes it or not and then decide whether he likes it or not afterwards. So we see that quite a lot.</i>
	Encourages and supports the child to be involved in extracurricular activities	<i>I like tennis and soccer, they're the sort of things I grew up with and I encourage the boys to be involved in those sorts of things as well, involved in sports and outdoor activities and be as physical as they can.</i>
	Helps the child establish relationships and encourages communication with others	<i>Sometimes Paxton has friends sleep over... We try and encourage a lot of play dates with the kids.</i>
Participates in school activities and helps with school work		<i>Well my involvement is homework, as you would with any kid. Making sure it's done, helping them out, checking it, educating them more, giving them other activities if you think they're interested in it.</i>