

Factors influencing parents' decisions about communication choices during early education of their child with hearing loss: a qualitative study

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Abstract:

Objective: To explore the factors influencing parents' choice of communication mode during early education of their child with hearing loss.

Design: Qualitative descriptive analysis of semi-structured interviews of parents of children with hearing loss.

Study Sample: Fourteen parents of children who participated in the Longitudinal Outcomes of Children with Hearing Impairment study.

Results: Four themes emerged from thematic analysis of the interview data: (1) parents draw on a variety of experiences and information to make decisions; (2) parents' preferred outcomes for their children drive their choices; (3) child's preference and proficiency drive parental choice; and (4) parents' fears and worries influence decisions. Parents required unbiased, descriptive information as well as evaluative information from professionals, so that they could consider all options in making a decision that met their needs. They required continual support for implementation of their choices as they adjusted to their children's changing needs.

Conclusions: Decisions around communication mode are rarely made in isolation, but occur within a larger decision-making matrix that include device choices, early intervention agency choices and "future-proofing" the child's future communication options.

Permanent childhood hearing loss (PCHL), which affects 1-3 in every 1000 life-births, has a negative impact on children's development. Early detection through universal newborn hearing screening (UNHS) programs offers opportunities for early access to hearing devices and specialized communication intervention. There is now clear evidence that supports the effectiveness of early fitting of hearing devices (Ching et al., 2017) and early enrolment in specialized intervention for improving outcomes (Holzinger, Fellingner, & Beitel, 2011; Vohr et al., 2011; Yoshinaga-Itano, 1999). While decisions about device fitting are guided by evidence-based protocols on audiological management (American Academy of Audiology Task Force on Pediatric Amplification, 2013), there is a lack of high-quality evidence on how communication skills can be best learnt or taught in the presence of hearing loss (Fitzpatrick et al., 2016). The evidence published on communication choices have focused largely on children and adolescents with severe or profound hearing loss, which cannot be generalized to infants with different degrees of hearing loss detected early in life. As the evidence is limited in scope and dated, there is a need to investigate into communication choices for children with wide ranging degrees of hearing loss identified at a very early age.

A major question faced by parents after diagnosis of their children's hearing loss is to decide whether their children's speech and language skills can be best developed by focusing on use of speech and/or sign for communication (Marschark et al., 2007; Seaver, 2010). This decision is especially challenging for those parents who have no prior knowledge or experience about hearing loss and/or communication modes other than the use of speech alone. Given that more than 90% of children with PCHL are born to hearing parents (Mitchell and Karchmer, 2004), there is a need to increase understanding of factors that may influence parental decisions on communication modes and the processes involved in parent decision-

making so that effective family-centred intervention programs can be developed (Gavidia - Payne and Stoneman, 1997).

Previous investigations of parental decisions on communication choices have used questionnaire-based surveys, with studies including a wide age range of children who have severe to profound hearing loss or using cochlear implants (Bruin and Nevøy, 2014; Decker, Vallotton, & Johnson, 2012; Guiberson, 2013; Li, Bain, & Steinberg, 2003; Steinberg, Bain, Li, Delgado, & Ruperto, 2003). Li et al (2003) surveyed 83 parents of children with hearing loss ranging in age from 5 to 18 years, showing that severity of hearing loss was the major factor influencing parental decisions. In this study, parents' belief that deafness is a condition that can and should be corrected, and their desire for their child to speak were important factors influencing the choice of an oral mode of communication for their children with PCHL.

Steinberg et al (2003) reported on a survey of 29 Hispanic families on communication mode and oral bilingualism for their children with PCHL. The children ranged in age from 4 to 14 years, with a mean age at identification of hearing loss of 24 months. Twenty-three of the 27 children had severe to profound hearing loss. The study showed that factors influencing parents' decisions on communication mode included professional advice (96%) and services provided by schools (86%) attended by their children.

In regards to sources of information influencing decision making about communication mode, Decker et al (2012) used an online survey to investigate the effects of sources of information, parental values and knowledge about communication development on their decisions on communication modes for their children with PCHL. Responses were received

from 35 parents (30 parents had typical hearing) of children with a range of hearing loss (more than 65% of children had severe or profound loss). The children ranged in age from 0.3 to 9.3 years, and the age at identification of PCHL ranged between 0 and 77 months. Most parents (>71%) reported that the most dominant source of information was from medical professionals, audiologists and speech pathologists, followed by internet (63%), and then school teachers. Logistic regression analyses of responses revealed that after controlling for child characteristics and parental knowledge, parents' values significantly predicted their communication choices. Parents identified their own judgment and the opinion of the other parent of the child to be most influential in their decision-making. Parents who chose to use speech alone with their child had views that deafness needs to be treated, and had received information from audiologists or speech pathologists significantly more often than those parents who chose to include signs in communication with their children.

Guiberson (2013) examined factors influencing decisions on communication mode and oral bilingualism in 71 Spanish parents of children with PCHL. Most children had severe to profound hearing loss, with 69% of them using at least one cochlear implant. Fifty-five percent of the parents selected an oral mode of communication for their child, 24% selected an oral plus sign mode, and the remaining selected cued speech. Parents reported that spouses/partners were most involved and supportive in the decision-making process. Professionals who were most involved and supportive were speech-language pathologists, audiologists and deaf educators. Seventy-one percent of respondents indicated that the type of services provided in schools was a very important factor when making decisions about communication mode, with 40% indicating that availability of services close to home as very important. There were no significant differences in family involvement, professional involvement and supportiveness among groups using different communication modes.

Bruin and Nevøy (2014) reported responses to an open-ended on-line questionnaire about choice of communication options from 27 hearing parents of children using cochlear implants, aged between 1 and 14 years, in Norway. All families used spoken language at home, 14 of them also used Sign Supported Speech, and four of them also used a sign language. A qualitative analysis of the written accounts provided by parents revealed that the discussion at post-diagnostic follow-up was perceived as implying that there is a 'right' and 'wrong' choice, and that the 'right' choice will lead to 'success' with regard to spoken language development. It was found that being presented with strongly opposing opinions about what the 'right' choice might be was stressful for parents.

In a population-based study on outcomes of children with hearing loss ranging from mild to profound degrees in Australia, the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study, Ching et al (2013) found that the use of an oral mode of communication during early education was associated with an effect of 4.5 points in language scores at 3 years (95% confidence interval: -5.4 to 14.4), and the use of an oral mode of communication at home was associated with an effect of 3 points in language scores (95% confidence interval: -2.2 to 8.1). This provided the context for an exploration of factors influencing decisions of parents of the LOCHI study cohort by using a custom-designed questionnaire, as reported by Crowe, Fordham, et al (2014). The study analysed responses from 175 parents regarding decisions about use of speech or sign. When making decisions about use of speech, the parents' own speech skills (96.9%), and their desire for their child to speak to family (91.2%) and friends (91.2%) were important factors. When making decisions about use of sign, the desire 'for the child to participate in the hearing culture' (the specific term 'hearing culture' was used in the original questionnaire survey to encompass 'Deaf

culture' as well as other cultures related to hearing) (63.5%), the child's ability to form friendships in future (62.2%), and the child's future literacy and academic success (55.4%) were important factors. To explore relationship between influences on decision making, factor analyses on parents' responses to items describing child-related influences on their decisions about use of speech or use of sign revealed that 'the age at which their children 'first received hearing aids', and their children's 'future access to rewarding employment' accounted for 76.5% variance on decisions about use of speech, and 65% variance on decisions about use of sign. In a thematic analysis of the written comments in the questionnaire responses, Crowe, McLeod, et al (2014) reported that information from family, friends, other people with hearing loss, and professionals was most influential. Other factors included the practical need to communicate with their children, the proficiency of their children using the communication mode, the desire for their children to be part of the world around them and the wish for their children to develop normally. These findings provide insights into the relative importance of a range of factors influencing parents' decisions.

The questionnaire-based surveys revealed that a range of factors influenced parental decisions, including advice and information from professionals, family and friends (Bruin and Nevøy, 2014; Crowe, Fordham, et al., 2014; Decker, et al., 2012; Steinberg, et al., 2003), characteristics of the child's hearing loss (Crowe, McLeod, et al., 2014; Li, et al., 2003), expectations for their children (Crowe, Fordham, et al., 2014; Crowe, McLeod, et al., 2014; Li, et al., 2003), practical communication needs (Crowe, Fordham, et al., 2014), availability of services in schools and close to home (Guiberson, 2013; Steinberg, et al., 2003), own judgment and personal values or views on deafness (Decker, et al., 2012). As the methodology adopted in questionnaire-based studies typically required that parents' responses be fit into pre-determined categories for analyses, the studies do not explain how

the identified factors contributed to the decisions on communication choices, nor describe how these factors may be influenced by other variables.

It has been recognised that qualitative interviews can be used to verify and validate parents' perspectives. Eleweke & Rhodda (2000) reported two case studies - typically hearing parents of children who have severe to profound hearing loss. Both children were diagnosed at an age older than 2 years, one was using speech only for communication and the second one was using sign only. Qualitative analyses of semi-structured interviews revealed that the type of information provided to parents about communication options and functionality of hearing devices influenced their decisions. Further, the competence or philosophies of professionals who provided information to the parents also influenced their decisions. The parents reported that they were presented with unbalanced information (limited to one option instead of detailed information on all available options), leading to frustration and unrealistic expectations (functionality of hearing device). The study highlighted the need for relevant, unbiased and accurate information to be presented to parents in terms they can understand to support them in the process of decision making (Welch, 1996).

Steinberg et al (2003) reported on the results of a study using semi-structured interviews with 27 Hispanic families, showing that different communication modes were rarely discussed, and in 63% of the cases (17 out of 27), a combination of sign and speech ('total communication') was the only option offered by the school or county in which they lived.

Hyde and Punch (2011) also reported findings from interviews of 27 parents of children who ranged in age between 1.5 and 25 years using cochlear implants, showing that they placed a premium on communication through whatever means proved helpful for their children. Some of the parents considered that signing helped with their children's spoken language

development, provided a means of communication when children were not using their cochlear implants, and contributed to their children's social participation and their Deaf identity.

Borum (2012) used semi-structured interviews to explore Afrocentric cultural influences on communication choices of 14 parents. The African American parents had children ranging in age from 2 to 17 years who had been diagnosed with hearing loss (6 had severe to profound hearing loss, 4 had mild to moderate loss, and the hearing level for 4 was unknown). The hearing parents expressed a strong preference for their child to access the oral language tradition in their culture. Concurrently, they also wanted their children to be able to interact with hearing and Deaf communities. They wanted their children to access written English language, and also to share their racial, ethnic and cultural heritage. The study reinforced the influence of values, including cultural and socialisation aspects, on parents' decisions.

These qualitative studies lend support to the important influence of information from professionals and family, but revealed that in some instances, professional advice could be conflicting, biased, opinionated, and limited in scope, thereby leading to parental stress or frustrations (e.g. Bruin & Nevøy, 2014; Eleweke & Rodda, 2000). The parents' values, including their perception of the implications of hearing loss and communication choices on the family and on their children's development and outcomes also affected their communication choices. In addition, implementation concerns, including accessibility and availability of services influenced parents' choices about communication mode. These findings are consistent with the three elements that underlie the making of an informed choice – a decision that is 'based on relevant knowledge, consistent with the decision-maker's values, and behaviourally implemented' (Marteau, 2009).

As most previous studies have considered perspectives of parents of children with severe or profound hearing loss or those using cochlear implants, there is a need to gain a broader understanding of the factors influencing communication choices of parents of children with diverse hearing and demographic characteristics. Given that parents' perspectives of communication modes change over time with changes in their children's needs as they grow (Watson, Hardie, Archbold, & Wheeler, 2008; Wheeler, Archbold, Hardie, & Watson, 2009), the perspectives of parents of children that ranged widely in age up to young adulthood reported in previous studies are likely to vary from those of parents of young children who commenced intervention at an early age.

The current study

This study aimed to increase understanding about perspectives of parents of children with hearing loss ranging from mild to profound degrees on factors influencing communication choices in early specialised intervention for their children. By placing research participants' experiences and their perceived needs at the centre of knowledge development and validation, and by recruiting a sample with wide ranging experiences drawn from different geographical locations, we aimed to capture both common and unique approaches used by parents of children with hearing loss in communication choices (Patton, 2002). We used qualitative semi-structured in-depth interviews to collect data comprising narratives that 'revealed respondents' level of emotion about what is happening, their experiences and their basic perceptions' (Patton, 2002, pp. 22-28).

In Australia, all families with children newly diagnosed with hearing loss are referred to Australian Hearing (AH), the only service provider funded by the federal government to

provide audiological services and technology to children with permanent hearing loss, under the age of 26 years, at no cost to families. The families also receive information about hearing loss, technology, early education services and communication choices from AH.

Approval for this study was granted by the Australian Hearing Human Research Ethics Committee, which is registered with the Australian National Health and Medical Research Council (NHMRC) and operates in accordance with the NHMRC National Statement on Ethical Conduct in Human Research(2007 (Updated 2018)).

METHOD

Context of the study

Participants of this study were parents of children in the LOCHI study. The LOCHI study was designed to examine the speech, language, psychosocial, and functional outcomes in a population-based cohort of Australian children with PCHL who were born between 2002 and 2007 and who first received intervention from AH before 3 years of age (Ching et al, 2013). About 450 children were enrolled in the study at 5 years of age, all of whom were residents in the states of New South Wales (NSW), Victoria (VIC) and Queensland (QLD) at the time of birth.

Sampling

Parents of children who attained a nonverbal cognitive ability score of ≥ 85 when assessed at 5 years of age using the Wechsler Non-verbal Scale of Ability (Wechsler and Naglieri, 2006) were invited to participate in this sub-study that focused on children with no additional disabilities. Eligible families were sent a letter of invitation, information statement and expression of interest form with a reply-paid envelope. Researchers phoned families that

expressed an interest to provide further details about the study and to obtain consent.

Sampling was designed to seek variation in terms of type of communication approach used with the child, type of early intervention setting the child attended, the child's degree of hearing loss, type of hearing devices used by the child, and geographical location (the Australian state of residence).

Participants

A total of 14 families were recruited for this sub-study to offer diverse perspectives and capture patterns that are common among cases explored (Patton, 2002). Other studies of a similar nature have reported reaching saturation after collecting qualitative data from a similar number of respondents (Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Guest, Namey, & Mitchell, 2012). Ten families lived in Victoria (VIC), two in New South Wales (NSW), and two in Queensland (QLD). . At the time of the parental interview, the children ranged in age from 6;6 (6 years 6 months) to 10;0. Table 1 outlines the demographic characteristics of the children and parents/ caregivers.

[Insert Table 1 about here]

Data Collection

After written consent was obtained from a family, a researcher conducted a semi-structured interview with each participant. One parent from each family attended a face-to-face interview conducted in spoken English at a location convenient to the family (i.e. family home, child's school). At the time of the interview, the researchers were blinded to the communication mode used with the child during early intervention, the early intervention agency the child attended, the degree of hearing loss and the language outcomes of the child

as much as possible.. The researchers were known to the families through their participation in the LOCHI study.

The interviews were guided by a list of probe questions, including the parents' journey from when their child was first diagnosed with PCHL, the ways in which they had gathered information and made decisions about communication modes and early intervention agencies, their experiences and perceptions of their children's communication and intervention, and their expectations for their children's development. The questions in the interview guide were open-ended, and the interviewer was free to explore, probe, and ask questions about unanticipated responses that were relevant to the subject under research (Patton, 2002). All interviews were audio-recorded, with permission from the participants. Thirteen (93%) of the parents interviewed were the mother, and one was the father. The interviews had a mean length of 58 minutes (range: 34-86).

Data Analysis

All interviews were transcribed verbatim by a third party in a de-identified form, and pseudonyms were used for participant names. Thematic analysis, as described by Braun & Clarke (2006) was undertaken, with initial coding of 10 of the 14 interview transcripts to identify broad thematic topics and concepts in each interview that were relevant to the study research question. The first step involved familiarisation with the content of the transcripts. The next step identified the key excerpt lines related to communication choices. These data were coded, leading to the development of categories, which were revised and subsequently grouped into themes. In order to increase the rigour of data analysis, two researchers (JSK, VM) analysed two transcripts independently and compared and discussed coding strategies. Through an iterative process, the researchers met with the first and second authors (TC, NS)

to discuss the findings and to refine the categories and themes. The final set of themes was verified by recoding all 10 initial transcripts and four new transcripts. This process was used to validate whether themes not extracted from the 10 transcripts might emerge or whether a saturation point had been reached. Seven codes not previously identified in the initial coding process were identified in the four new transcripts, however discussions among researchers revealed that these new codes aligned with the existing categories and themes, and thus these codes were integrated into the existing framework.

RESULTS

Four themes emerged from thematic analysis of the interview data, which captured the experiences and perspectives of parents regarding factors that affected their decisions on early intervention service and communication mode for their children: (1) parents draw on a variety of experiences and information; (2) parents' preferred outcomes for their children drives choices; (3) child preference and proficiency drive parental choice; and (4) parents' fears and worries.

Theme 1: Parents draw on a variety of experiences and information

Analyses of the interviews revealed that prior experiences and information from various sources influenced parents' decision making. This theme incorporated four sub-themes, each of which are discussed below and summarized in Table 2 with example participant quotes.

Experiences with early intervention services.

Parents' initial experiences with early intervention agencies (EIAs) influenced their decision-making process. Specifically, parents referred to their familiarity and rapport with the service,

their direct involvement with the service, and the family-centredness of the service. Two families in particular reflected on how their first contact with the staff at an agency guided their choices:

'[Laughs] But she came out to see me and she was, um, she was just so nice and, you know, reassuring and everything else. And I think out of everybody, she was the – the one person that, you know, like, is what I needed at that time. Because after just being told all of this, she was like, "Oh, well, you know, now we need to make sure that we get early intervention in and we do as much as we can," and she's the one that said to me, "You've got a timeframe." "From now 'til he's five, get as much language in as possible. "So, anyhow, the way she spoke to me was really good. So then I basically started seeing them and taking him to play groups and everything from eight weeks old.' [470].

A second parent recounted how her first visit to an EIA helped her to make a decision *'I knew we were getting a hearing aid – – and then I started ringing around — and I rang [EIA] and they said, "Oh, yeah. Bring her out." ... Well, they were quite accepting and they — just said, um, and they said, "Well, yeah, we've got – we have got a couple of other people coming for a playgroup so come — see what you think."– and, um, that was it.'* [245]. The experiences parents earned once their child commenced in an agency served to validate their decisions on the service provider and communication mode *'But they [EIA_B] were fantastic. They – they made it really easy for me.'* [386], *'Yeah, [EIA_A] were magnificent.'* [627]. Another parent indicated, *'I just knew I would have gone, yep, back to [EIA_A], um, and done everything that I did cause I know that it works'* [235]. In a similar vein, a third parent said, *'Um, and [EIA_B], like, I think we had the best teacher of the deaf in the whole world'* [834], *'it ended up being the perfect place so we just stayed there.'* [831], and a fourth parent affirmed their

choices *'So – and I think – I don't know, if I had have gone anywhere else, I really don't think [child] would have been the way he is. They gave me the right tools to work with. Um, you know, and the advice and — friendship and everything else.'* [470].

Experiences around accessing information.

When making decisions about EIAs and communication modes, the information available to parents clearly played a role. Parents accessed information through a number of sources, including online and directly through services. *'In terms of [hearing provider], I find that they sort of stayed by policy so they won't provide you with too much information ... so the information that I am getting is off the Internet'* [337]. As indicated by a parent: *'There wasn't a lot of information at that point so I tend to well Google'* [337]. Although some parents reported accessing information from a range of sources, others relied solely on the information provided by services: *'I'm not the sort of person that will look everywhere ... I'm not going to even bother looking into the other places unless I find this place isn't working for me and my child, and then I'll look somewhere else ... and it ended up being the perfect place so we just stayed there'* [831]. Indeed, some parents reflected on the wealth of information they received from the EIA their child attended: *'If I had any questions or wanted any information I could always ask and they were always happy to give me any kind of information that I needed or wanted'* [386].

On the other hand, some parents reflected on their lack of knowledge of alternate services and modes of communication: *'I don't know what any other avenues are ... I forgot what other pathways I could have taken, and I'm sure they're good too'* [235] and *'I honestly can't*

remember. I just remember someone giving me a list of service providers and we had to choose which one' [834].

Drawing on family and friends.

Parents relied heavily on the support of family and friends, and indeed other families, when making decisions about communication mode and early intervention services for their child. Some families had a history of hearing loss in the family, and that influenced their decision making *'because I do have brothers and sisters that are deaf. It is in my family and everyone was very understanding I suppose' [386].* For parents who had older children with hearing loss or other communication disabilities, their prior experience with services and early intervention professionals also influenced their decisions: *'We were very keen to have a speech therapist because my son had been to speech therapy too so I guess that was a familiar thing and we thought yes, she probably will need that too' [380].* Family communication mode also played a role in the decision making process: *'They [friends with CI] said "Do you want your son to hear, to hear like his, you know, sisters and brothers, or do you want him to use sign language"' [627].* Family and friends also played a role in supporting the decision by completing sign language classes. Other families also played a role in influencing parents' choices: *'We hooked up with them [EIA service] and just started to meet some people and just chat to them and just talk about their experiences and that was really, really helpful' [834]; 'That was great in terms of educating me and having other parents. ... they do help you through those various stages of processing it and the personal support as well as the practical support' [337].*

Drawing on professional advice.

Parents gave weight to the advice they received from professionals, for example from the EIAs their children were attending *'They would understand Rosalie's needs because they were a professional in that area... and I trust – because I've had a relationship with [EIA_A] — too, everything they've ever told me, I've always trusted it to be the best source of – ...information'* [235], and *'Um, that was really, ah, talking to the [EIA_C] and going on their recommendations.... Um, so – um, and their experience so they – they pretty much just recommended trying the – the oral... Otherwise I probably would have tried, um, signing – as well'* [337]. Parents reflected that they followed the advice of professionals: *'So it wasn't really – like, we weren't forced to go there (EIA) but we were just in shock and – and he said, "Go there tomorrow," and we sort of said, "Okay." (Laughs)...Because we just didn't – we didn't know what to do. It was just – and – and at that stage you don't know what to do so sometimes you just do what you're told to do'* [831]; even when it challenged their personal goals for their child *'If I had to – if they had recommended that she went to a school with a hearing unit, then – or went to kinder at [EIA_A] then I would of for her benefit but everything was fine so we were able to mainstream her, which is what we wanted to do.'* [831].

Professional opinions were sought not only for selecting a communication mode, but also for selecting the spoken language to use with children in multilingual households. One family whose parents spoke English and Arabic at home commented *'[EIA_A] kind of said it would just be easier if he just learnt the one language first...You know, because when we went to [EIA_A] obviously they were teaching him English.... So we had to bring what we learnt*

there home and teach him the same things, like, in English...If we were to teach in Arabic it would be all over the place.' [627]

[Insert Table 2 about here]

Theme 2: Parents' preferred outcomes for their children drive choices

Parents' communication goal for their child appeared to drive their choices of their child's mode of communication and EIA. Seven sub-themes are discussed below, and summarized in Table 4-3 with examples on quotes from participants.

Device choice.

Parents made their choices regarding their child's device secondary to their chosen communication goal: *'If you want him to hear there's the cochlear implant and if you don't want him to hear, there's the sign language, but of course we wanted him to hear. And that's when we decided on the cochlear implant'* [627]; and parents saw the device as a means to an end *'She just, she needed it, so that's what's given her normal speech'* [235]. Parents also sought advice from other parents: *'I tried to find people that have had 'em [hearing device], what they think of them'* [372]. When discussing their decision to give their child a cochlear implant, parents reflected on their perceived limitations of hearing aids: *'Even though people were encouraging us to keep using them, my instincts just told me it just wasn't working for him'* [834].

Of interest was that throughout the interviews, parents commonly validated their decisions about their child's device by either comparing their child's outcomes with those of others: *'Now that I have experience with [child], I can tell that one of them [nephews] would have benefited from a cochlear implant because his speech is just not very clear and is hard to understand'* [235], or reflecting positively on their child's progress with the device *'With his bionic ear, he's just like a normal little boy'* [386].

Knowing which early intervention service they want.

When reflecting on their decision-making processes, parents referred to how they sought and accessed information about services that aligned with their chosen communication goal: *'Um, so they told us about [EIA] and I decided, I knew straight away, that yep, we would do that'* [235]: *'They came out [preferred EIA service] and then I knew, I don't want that, I want that'* [627]. *'We knew what we wanted and we decided we'd try [preferred EIA service] because of the signing'* [833] and *'Because that was the choice over at [EIA service], they did sign. Um, whereas [preferred EIA service] was total auditory verbal therapy. Which obviously, having no other hearing impairment around us, we felt that was an easier option for everybody in our family'* [212].

Service accessibility.

The location and accessibility to services played a role in the decision-making process: *'It was just too far to realistically consider it, yeah it would have been a real issue to try and get there'* [337] and *'The distance that I would have had to have travelled would have just been*

too much [386]. Interestingly, parents referred to the role ‘zoning’ played in their decision making process, acknowledging that their location affected their eligibility to attend certain services: *‘I did hear briefly about the other agencies ... but because it’s all to do with zoning, so if you live here, you access this. You know if you live here you access this ... you’re just put into regions’* [372]. This parent subsequently moved so her child would be eligible to attend a particular service: *‘So I found out at the time that [preferred EIA service] probably had the best options for [child] so I moved from [location] back to Mum’s house in [location] and that got her enrolled’* [372].

The availability of home visits factored into some parents’ decisions: *‘Plus, they [preferred EIA service] came to home, and with having the two girls and they [alternate EIA service] were very much “No, the girls can’t really come to appointments” so part of it was that [preferred EIA service] came to home’* [827].

Self-investment to achieve goal.

Parents noted that their choice of communication mode and EIA was influenced by the degree of self-investment they were able to commit to in order to achieve the desired outcomes. Parents made extra time and juggled work commitments as part of the decision making process: *‘Lots of appointments. But yeah, it was all achievable’* [212] and *‘We took time off work and we were always there’* [380]. Parents referred to the personal investment they made in their child’s outcomes: *‘You do what you have to do’* [627] and *‘Just give the kids as many options as you can ... never leave any door closed. Open everything for ‘em’* [372]. Some parents noted they left or changed their place of employment as part of the

decision making process: *'I actually work as a teacher of the deaf. I started studying a year after [child] lost her hearing. When we found out that [child's] hearing was going to be progressive, I quit my job and wanted to help her as much as I could and learn as much as I could'* [380]. At the end of the day parents noted *'you've got to sacrifice ... if you really want him to progress, you have to drop everything and just do what needs to be done for him'* [627]. *'I thought I had to give her the best start possible, and if that means giving up all my time ... then so be it because this is my daughter and I have to give her the best start in life'* [234]. Parents throw themselves into helping their child in any way possible with the chosen intervention and communication path, often with a huge amount of self-sacrifice *'I was really focussed and just kept doing everything that was sort of thrown at us or offered to us'* [834];

Child must be seen as "normal".

Parents were driven in their decision-making process by the desire for their child to be seen as "normal": *'Its [oral approach] like the most normal upbringing for a child without excluding them from other family members that can hear ... everything I did for her is coming out now as a normal child, as normal as she can be'* [235]. Parents were driven in their decision by their desire for their child to communicate in the same way as others: *'Knowing that we could communicate ... because that was probably the scariest bit, was thinking that he's going to be different from everyone in his family'* [386].

Oral communication goal.

Related closely to the sub-theme of wishing their child to be seen as “normal”, there was always the goal for some parents that their child would use an oral mode of communication, and subsequently aligned their choice of early intervention agencies to fit in with this goal ‘...and I just went home and looked at the book and go, “Oh, well, I don't know what she needs. Does she need signing? Does she not need signing? Does she...?” And I just rang [EIA] because I thought oh, well, they're offering no signing, she doesn't need it.’ [833], and ‘Yeah, they [EI] sign, yeah? Yeah, they came out and as a m – as a mother you just know that nup, you don't want to do that. I don't know why I put it in my head, I don't want to sign.’ [627], and ‘No. No. Always, um, spoken language.’ [470]. Some parents who opted for an oral only communication goal early on in their child’s life held the belief that sign would only be considered as a ‘plan B’ for their child, for example, ‘we want to go through the process of a cochlear implant first and if that doesn't work for us for whatever reason, we will sign and go down that path’ [831]

Bilingual communication goal.

There were parents who were open to adopting a bilingual mode of communication with their child early on ‘a girlfriend had done some signing with her daughter who was the same age as (child) and when – so, when (child) wasn't having as much language...we did a lot of baby sign with him.’ [827], and ‘um, so we decided because he was diagnosed – (child) was diagnosed so young, didn't really have any language, and at that point, um, we thought we'd go through (EIA) because they encouraged signing and Auslan... So I thought because even with a hearing child, signing can be a way of them communicating more effectively’ [833]. Others, however, were worried about their own proficiency ‘Yeah, and I was worried, how am I going to learn the sign language? It's going to be hard for me’ [457],

The choice of using sign early in a bilingual approach was validated upon reflection by one parent *'Um, well, from our experience, I think I would definitely use Auslan in the early days until you can, um, [pause] until you can be certain of what, um, their getting, you know, as far as they're oral – I mean, their auditory, um, input. I think as – until you can ascertain what level they're getting and how well they can communicate that way, I just think that you just really have to use Auslan.'* [834].

[Insert Table 3 about here]

Theme 3: Child preference and proficiency drive parental choice

The third theme to emerge from analyses of the interviews was how child characteristics influenced parental decision making in communication mode, or drove a switch in communication mode over time. This theme incorporated two sub-themes, detailed in Table 4 and discussed below.

Child preference.

Changes in communication mode over time were sometimes driven by the child's own initiative *'Um, we, probably not at that initial time but probably when [child] was in prep, um, [child] started to want to learn sign language and we hadn't wanted to go that route but [child] started teaching herself the alphabet and, um, showed an interest in making up her own language. So we tried to embrace that a bit more'* [380]. The child's preference guided the communication mode to be used, either to start signing: *'Um, and he really enjoyed signing and we enjoyed it too'* [827], or to use spoken language *'But, ah – but she's sort of independently moving away from the sign-language'* [372].

Changes in communication mode were driven by the child's preference '*As he got more into kinder, um, and school that the signing has dropped off.*' [833], or by the parent '*But we, um, did sign language probably until he started going to kinder. Then we really tried to use his words and stuff instead of sign language*' [386].

Child Proficiency.

The child's progress with a given communication mode or in a particular EIA became a reason to continue with either speech only '*Like, she seemed to progress and almost to the point where six months down the track they were saying she was almost age appropriate. Like, she just – the gap was really big and then she seemed to close it really quickly, if that makes sense.*' [831], or with the use of speech and sign together '*And then what we actually found was, once she learnt what – how to – how to say "book", and we could actually finger-spell it, BOOK. And where later on down the track like now, when she sees a book, she automatically knows what the sign is... So it's actually she can do the both, the – the picture and the words. And I think it just opens that up for her.*' [372]. The child's progress also becomes the validation for the parent that their choice was right for their child '*It may not be for everybody and there've definitely been people that we've spoken to who haven't been overly happy with them but for us it was the right choice...and then she even surpassed in some areas.*' [212], and '*I just knew I would have gone, yep, back to [EIA], um, and done everything that I did cause I know that it works*' [235]. Other parents, however, ruminated on whether they had made the right choices for their child '*and I still think about it now with [child] is should I ever teach her sign language? That's what I – I just wonder*' [235].

For parents whose child had a post-lingually diagnosed hearing loss, the child's language skills prior to diagnosis influenced their decision regarding communication mode: '*Look he*

had some language, because if he had no language, I would have done something but he had enough and he followed instruction' [827].

[insert Table 4 about here]

Theme Four: Parental fears and worries

The final overarching theme that emerged in our analysis was the parent's fears and worries about their children's hearing loss, development, and whether their child might be accepted in society. This theme is made up of three sub-themes described below, and in Table 5.

Fear around hearing loss.

The unknown benefits of hearing devices, such as cochlear implants, clearly played on some parent's minds *'And you're thinking to yourself, "They – they're not supporting themselves pretty well. All they're saying is 'this can go wrong and this can go wrong'." And it's sort of – it's – you don't know and it's that – that not knowing that's the part – the scary part' [372].*

Uncertainties around the impact of a progressive hearing loss also is at the forefront of one parent's minds *'I wasn't coping. Um, and figured that we needed to focus on [child] developing her language really quickly. Um, we realised that it was really – you know, it's a critical period for everybody to develop language but especially for [child] we didn't know how long she would be able to hear for' [380].* Over time, parents come to accept hearing loss, perhaps more so for those whose children appear to be developing normally *'because [sister_1] has her scoliosis and [sister_2] can't eat wheat 'cause she has eczema from that, I just made it up that everybody has something and that his was hearing aids.' [827]*

Society's acceptance.

Some parents experienced a lack of community support for their child who used hearing aids. A parent of a child who has unilateral hearing loss and using one hearing aid reflected: *'the lovely lady at nursery used to say, "Madam, I didn't put her hearing aid back on after we did swimming because she can hear, she's fine." Okay. All right.[Laughs]. So...That was – yeah, that was about it.'* [245]. Another parent reflected on difficulties accessing services in the community *'I wanted him to learn swimming and I found that very difficult. Um, because having his ears off in the water meant that I would need a sign language swim teacher.'* [386]. Parents worried about how the physical appearance of hearing devices worn on their child might be perceived by the society, particularly early in the child's life *'Um, she's – she's lucky in that she's, um, she's quite pretty so she's got big blue eyes and blonde hair so she's always got really good reactions from people, even, um, with the hearing aids.'* [337].

On the other hand, there were comments about positive support in the community. A parent reported on unexpected support when their child who had used a bilingual approach in early intervention proceeded to a mainstream school. *'When she did start at [school] they had a – um, [teacher name] – I can't remember his last name now. He's a Auslan teacher.... And he physically come to the school and ran a series of Auslan classes. Um, Certificate One or whatever it was called... And so 20 of the teachers here got involved into it all. Ah, the school paid for – for him to come here just to help [child] and we all done that participated in it all and, um because we find here that 600 kids here are so interested in it and they want to be able to talk to her and, um – they're just so eager to learn Auslan'* [372].

Practical communication needs.

Parents expressed worries about communication needs of their children: *'Well, first I was scared that she's never going to talk, I'm never going to hear mum from her.'* [457], *'and*

that's why I say I wonder if she should learn sign language, because if something ever happens in the world and I – I need her to be able to communicate somehow. That's the only thing. And it might sound silly, but I think that's just me being a mum to a deaf child, just thinking all these things that can go wrong' [235]. The practical need to communicate with their children led some parents to learn signs for communication 'to learn the Auslan, and then that way they could communicate, you know, if they wanted to go to the toilet or – so it was generally that was the purpose.' [372], 'I had to gesture when she was doing – when she's in the bath, gesturing. When she might go flat, I'm gesturing to her. If she happens to wake up, comes in and sees us before I get to her and she doesn't put her hearing aids on' [235].

[insert Table 5 about here]

DISCUSSION

Parents of children with PCHL have to make decisions about communication choices during specialised intervention very early in their children's life, preferably before 6 months of age (Joint Committee on Infant Hearing (JCIH), 2007). Making communication choices is especially challenging when most families do not have experience of communication modes other than speech, and there is a lack of high-quality evidence on how best to encourage language development in the presence of hearing loss. In this study, four themes emerged from analyses of interviews conducted with 14 parents of children with PCHL on their communication choices. Parents' decisions were influenced by 1) their experience and knowledge from different sources, 2) their preferred outcomes for their children, 3) their children's preference and capabilities and 4) their fears and worries. These four themes are

discussed within the framework of elements underlying informed choice (Marteau, 2009), namely availability of relevant information, consideration of personal values, and practical considerations in implementation.

Information

Parents identified their prior experience with intervention agencies, and information from family, friends and professionals as the sources of information that guided their decision making. This is broadly consistent with previous literature on communication choices (e.g. (Crowe, Fordham, et al., 2014; Steinberg, et al., 2003). Some parents reflected on how their first encounter with the staff at early intervention agencies and the rapport they built with the staff influenced their decisions. Prior experience of having a child with hearing loss or communication disorders also shaped their preferences and decisions.

In addition, parent-to-parent support was important. Meeting and sharing experiences of other families with similar conditions helped parents to gain more information about communication choices. Particularly for families of hearing parents who did not have prior experience with sign language, the current study showed that meeting other families that used sign language was a learning experience that helped the families to ‘process the new information’. However, personal experiences can bias parental decision making, and its role is complex and controversial (Bekker et al., 2013). A scoping literature review by Henderson et al (2014) proposed a conceptual framework for parent-to-parent support to contribute to early intervention programs through instilling well-being for families, knowledge advocacy, and empowering parents. These are important goals to achieve in the process of recognising the importance of providing parent-to-parent support (Joint Committee on Infant Hearing (JCIH), 2013).

The current study found that information provided by professionals has an important influence on parents' decisions, in line with previous studies (e.g Eleweke and Rodda, 2000; Scarinci, Erbas, Moore, Ching, & Marnane, 2017). Unlike some previous reports in which parents indicated that the information provided to them was often biased and selective, leading to frustrations and stress (Christiansen and Leigh, 2004; Decker, 2009; Steinberg, et al., 2003; Young, Jones, Starmer, & Sutherland, 2005), parents in the current study reported that they were provided with relevant information on options available to them. Nevertheless, they indicated that the information drove them to carry out further research on their own to assist with decision making. This highlights the need for professionals to not only deliver descriptive information about available options in an unbiased manner (Luterman and Kurtzer-White, 1999), but also to provide evaluative information to help parents understand the benefits and risks of each option and the probability of each occurring in order to assist families in their decision making (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013).

Values

Values are 'detailed insights into the patient's [parents of children with hearing loss in the present context] attitudes about the relative desirability of each of the possible benefits and harms – or attributes – inherent in each option.' (Llewellyn-Thomas, 2009). The current study found that parents had the best interests of their children in mind when making decisions about communication choices.

For some parents, the desire for their children to be perceived as 'normal' in the family and in society drove their decision. For others, the choice was driven by the practical need to

communicate with their child, and the uncertainties regarding changes in their child's hearing loss or the effectiveness of the hearing devices. Consistent with the findings reported by Hyde and Punch (2011), parents 'placed a premium on communication' and used whatever means proved helpful for their children. The parents who used signing to some degree perceived that it assisted with their children's spoken language development, and provided a means of communication when their children were not using hearing devices or when the devices were not working.

Regardless of initial preferences, though, children's communication preferences and progress continued to influence parents' choices and adoption of alternative options that met their children's needs. Some parents considered signing as an alternative only when oral communication would not work for their children. As was discussed in previous literature on children with cochlear implants (Watson, et al., 2008; Wheeler, et al., 2009), it appeared that changes in communication mode over time were largely driven by the relative effectiveness of audition and the parents' response to their children's changing needs. Future investigations will examine the factors influencing changes in communication mode during early intervention not only for children using cochlear implants, but also those using hearing aids.

Implementation

Parents have reported that in implementing their choices, they had to make considerable life changes, such as learning a sign language, changing their work arrangements, or quitting their employment. An understanding of the trade-offs parents are willing to make to achieve the goals they have for their children is an important aspect for professionals and parents to explore prior to making decisions (Llewellyn-Thomas, 2009, p. 123). Some parents reported that they had limited choices beyond the selected option due to considerations for the type of

service delivery, e.g. home visits, or travel requirements, or the communication modality preference of the service providers. This finding is consistent with that reported in previous studies (Bruin and Nevøy, 2014; Crowe, McLeod, et al., 2014; Eleweke and Rodda, 2000; Mulla, Wright, & Archbold, 2013; Sach and Whynes, 2005; Steinberg, et al., 2003; Uus, Young, & Day, 2015; Wheeler, et al., 2009). Parents also indicated that community support and social acceptance influenced the behavioural implementation of their choices.

Strengths and Limitations

The strengths of the present study included the recruitment of participants from a population-based study to incorporate diversity in parental choices, and methods of communication that were used by the participants' children. The participants were drawn from different educational backgrounds, socio-economic status, cultural background and geographical location, thereby allowing diverse perspectives to be captured (Jackson, Cheater, & Reid, 2008). Common patterns shared among the cases were explored. By focusing on parents of children during early years of schooling, we examined parents' retrospective accounts of their early experiences soon after diagnosis.

A possible limitation of this study was the retrospective nature, as parents relied on their memories of early experiences. Parents were asked about how they made their initial choices, and their current perspectives. This explains why some comments appeared to be parents' validations of their own decisions through reflecting on their children's progress or comparing their children with others with normal hearing. There is the possibility that the parents might have provided different perspectives had their children's performance not

validated their initial choices. The study sample included parents of 10 children who used an oral communication mode, and 4 who used a combination of oral and manual modes of communication during early education. . As such, future studies will be necessary to investigate whether factors influencing parents' communication choices reported in this study might differ for families in which Auslan (or any other sign language) is used as the primary mode of communication. This study presented information about factors influencing choices of communication mode during early education of children with hearing loss. Some children changed communication mode over the first few years after diagnosis. Factors influencing the changes are reported in our companion article (Scarinci, Gehrke, Ching, Marnane, & L., This issue).

Conclusion and Implications

The current study adds to the growing body of literature in contributing to an increased understanding of parents' perspectives on communication choices for their children with hearing loss soon after diagnosis. Firstly, the findings extend previous studies by affirming the importance of providing parents with unbiased information about available options, but also reveal the additional need for evaluative information to assist with decision making. Increased efforts need to be directed to providing families with information on all available options and technology as well as evidence on the benefits (advantages) and harms (disadvantages) of each option to support informed choices.

Secondly, parents' initial choices were driven by their communication goals for their children, but they also readily adjusted to the changing needs of their children. Development of more family-centred approaches that acknowledge the central role of the children and family in the communication journey would provide continual support.

Thirdly, parents discussed 'sacrifices' they made and the importance of community support in implementation. The role of family-centred care in providing families with increased understanding of the consequences or attributes inherent in each option prior to making decisions is essential. Such approaches will empower parents to make informed decisions and to implement the option of choice (Charles, Gafni, & Whelan, 1999).

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Table 1. Demographic characteristics of children and parents

Child Characteristic	
Gender	
Male, n (%)	6 (43%)
Age of diagnosis	
Age (months), Mean (SD), range[]	9 (11.9) [1-32]
Device, n (%)	
Cochlear implant (CI)	8 (57%)
Bilateral hearing aids	6 (43%)
Age at first fitting of hearing aids	
Age (months), Mean (range)	11.1 (2-34)
Age at activation of cochlear implants	
Age (months), Mean (range)	21.4 (10-39)
Hearing loss	
4FA ^a hearing loss in the better ear, Mean dBHL (Range)	56.6 (22.5-86.25)
Information not available (Bilateral CI), n (%)	4 (29%)
Communication mode at home at 5 years, n (%)	
Oral Only	13 (93%)
Combined (oral and manual)	1 (7%)
Language used at home, n (%)	
English	10 (71%)
English + Other language	4 (29%)
Socioeconomic status	
IRSAD ^b decile, Mean (range)	7.4 (2-10)
Age at enrolment in early education ^c	
Age (months), Mean (range)	11.1 (3-34)
Hours of educational intervention (over five years)	
Hours, Mean (range)	228.9 (62.1-549.7)

Communication mode during education at 5 years, n (%)	
Oral Only	10 (71%)
Combined (oral and manual)	4 (29%)
Age of child at time of interview	
Age (years; months), Mean (range)	8;5 (6;6–10;0)
Parent Characteristics	n (%)
Child lives with	
Both parents	10 (71%)
One parent only	2 (14%)
One parent and their partner	2 (14%)
Parent reported hearing loss	
Mother has hearing loss	1 (7%)
Father has hearing loss	2 (14%)
Maternal education level	
University Qualification	3 (21%)
Diploma / Certificate	5 (36%)
7-12 years formal education	6 (43%)
Paternal education level	
University Qualification	3 (21%)
Diploma / Certificate	4 (29%)
7-12 years formal education	3 (21%)
Missing/ not reported	4 (29%)

^a 4 frequency average from 500Hz, 1kHz, 2kHz and 4kHz

^b *Index of Relative Socioeconomic Advantage and Disadvantage (Australian Bureau of Statistics, 2006), higher deciles indicate higher relative socioeconomic advantage*

^c *Early education includes intervention programs targeting speech and language development of children with hearing loss.*

Table 2. Theme 1: Parents draw on a variety of experiences and information

Sub-themes	Example participant quotes
Experiences with early intervention services	<p><i>I'm not the sort of person that will look everywhere, I don't know if I should or I – if it's the right thing or the wrong thing. Um, I'm not going to even bother looking into the other places unless I find this place isn't working for me and my child and then I'll look somewhere else. So – and it ended up being the perfect place so we just stayed there. [831]</i></p> <p><i>And I had looked at [EIA_B], um, earlier, probably 10 years earlier, when I was studying to be a kindergarten teacher. We were taken to [EIA_B] for a tour and seen this is a wonderful facility, and so I had that in my head. [380]</i></p>
Experiences around accessing information	<p><i>But I – I guess also, um, there wasn't a lot of information as well at that point. So um, I tend to – well, you – you Google. So...there wasn't a lot of information on babies and hearing aids. So I couldn't find anything on to – whether it would be beneficial or, um, I guess, um, you know, er, the implications of it or whether we should – whether there would be any benefits. [337]</i></p> <p><i>Um, and don't be afraid to, like myself, to ring up and ask people, you know. [372]</i></p>
Drawing on family and friends	<p><i>Um, I had heaps of support. Because I do have brothers and sisters that are deaf, it is in my family and – – everyone was very understanding, I suppose. [386]</i></p> <p><i>And because with his social group of babies, it was all, um, bilingual then, you know, in that area he was having that communication with other people. [834]</i></p>
Drawing on professional advice	<p><i>And I trust – because I've had a relationship with [EIA_C]— too, everything they've ever told me, I've always trusted it to be the best source of –...information. [235]</i></p>

Table 3. Theme 2: Parents' preferred outcomes for their children drive their choices

Sub-themes	Example participant quotes
Device choice	<i>Because without it [implant], there is no way she would be speaking as well as she is today, no way in the world. [235]</i>
	<i>If you want him to hear there's the cochlear implants and if you don't want him to hear there's the sign language. [627]</i>
Knowing which early intervention agency they want	<i>Um, and we found that – I liked that – going through [preferred service] because it was also home visits whereas [alternate service] was centre-based. [833]</i>
	<i>And they believe that coming to the home is the best way to do it because you've got a child in their own environment and, yeah, I think it was absolutely the best way to do it because he was always happy to have them here and he worked really well with them [834]</i>
	<i>Location was fantastic [212]</i>
Service accessibility	<i>Yes, um, I – I did hear briefly about all the other agencies. Um, but because it – it's all to do with zoning. So if you live here you access this. [372]</i>
	<i>Oh, I had to choose the ones that they can come home visit because I didn't drive that time. [457]</i>
Self-investment to achieve goal	<i>I thought I had to give her the best start possible, and if that means giving up all my time or whatever I was doing at the time, then so be it because this is my daughter and I have to give her the best, um, you know, start in life [235]</i>
	<i>You've got to sacrifice. You know, if you really want him to progress you have to drop everything and just do what needs to be done for him [627]</i>
Child must be seen as normal	<i>Well, I kind of thought that I shouldn't put too much emphasis on him being deaf. I wanted him to go like he was a normal child and</i>

	<i>that there would be little things that we would have to change to suit him, but I didn't want him to, um, necessarily go to a, a school for just deaf children. [386]</i>
Oral communication goal	<i>And then when we went to [EIA_B] and it was an oral focus and [child] already was talking because she's nearly three, that was the way we wanted to go and so there was no question in our mind that that was the right choice. [380]</i>
Bilingual communication goal	<i>So I thought because even with a hearing child, signing can be a way of them communicating more effectively. [833]</i>
	<i>From our experience, I think I would definitely use Auslan in the early days until you can...until you can be certain of...their auditory, um, input...until you can ascertain what level they're getting and how well they can communicate that way, I just think that you just really have to use Auslan. [834]</i>

Table 4. Theme 3: Child preference and proficiency drive parental choice

Sub-themes	Example participant quotes
Child preference	<p data-bbox="566 275 1468 474"><i>Um, we, probably not at that initial time but probably when [child] was in prep, um, [child] started to want to learn sign language and we hadn't wanted to go that route but [child] started teaching herself the alphabet and, um, showed an interest in making up her own language. So we tried to embrace that a bit more [380]</i></p> <p data-bbox="566 527 1438 600"><i>When we started at [school], we did a bit of signing after school but he really wasn't interested so it's really dropped away. [827]</i></p>
Child proficiency	<p data-bbox="566 615 1468 768"><i>Like, she seemed to progress and almost to the point where six months down the track they were saying she was almost age appropriate. Like, she just – the gap was really big and then she seemed to close it really quickly, if that makes sense [831]</i></p> <p data-bbox="566 821 1430 926"><i>It's like, oh – because the other boy wouldn't shut up and – then she started talking and now at home she could just ramble for about an hour and you're like, why did I teach you how to talk? [372]</i></p>

Table 5. Theme 4: Parental fears and worries

Sub-themes	Example participant quotes
Fear around hearing loss	<p><i>I wasn't coping. Um, and figured that we needed to focus on [child] developing her language really quickly. Um, we realised that it was really – you know, it's a critical period for everybody to develop language but especially for [child] we didn't know how long she would be able to hear for [380]</i></p> <p><i>...the audiologist comes back and he goes, "Your son's got a profound hearing loss." And I looked at my husband, "What does that mean?" Because you just don't know – I was terrible. Terrible. For a whole year I was depressed. Like, nobody would understand. I'd see other kids, I'd cry. I'd – I never wanted to leave home. [627]</i></p>
Society's acceptance	<p><i>... you get a lot of family members that say, "She's fine, she can hear. ...Or the lovely lady at nursery used to say, "Madam, I didn't put her hearing aid back on after we did swimming because she can hear, she's fine" [245]</i></p> <p><i>Um, she's – she's lucky in that she's, um, she's quite pretty so she's got big blue eyes and blonde hair so she's always got really good reactions from people, even, um, with the hearing aids. So they'll comment on – on, "Oh, aren't you cute?" [337]</i></p>
Practical communication needs	<p><i>And that's why I say I wonder if she should learn sign language, because if something ever happens in the world and I – I need her to be able to communicate somehow. That's the only thing. And it might sound silly, but I think that's just me being a mum to a deaf child, just thinking all these things that can go wrong [235]</i></p> <p><i>So I thought because even with a hearing child, signing can be a way of them communicating more effectively [833]</i></p> <p><i>Um, so basically I just hope that he can just be like everybody else, go through school, have fun and learn, you know. Fingers crossed he'll be something at the end of it all. [470]</i></p>