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ORIGINAL ARTICLE

Exploring how parents of children with unilateral hearing loss make habilitation decisions: a qualitative study

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ABSTRACT

Objective: This study sought to explore the decision making needs of parents managing the hearing and communication needs of children with unilateral hearing loss.

Design: An inductive, qualitative method was used. The data were analysed using a constant comparative approach, consistent with Grounded Theory method.

Study sample: Twenty one families participated in interviews yielding data on twenty two children. Each of these families had at least one child with unilateral hearing loss. The age range of the children varied from four months to sixteen years old. All parents were English speaking and received care from National Health Service Audiology departments across the United Kingdom.

Results: Parents valued professionals' opinions, but information provision was inconsistent. As their children mature, parents increasingly valued their child's input. Parent-child discussions focussed on how different management strategies fit their child's preferences. Parents were proactive in obtaining professional advice, and integrating this with their own iterative assessment of their child's performance.

Conclusions: Decision making is an iterative process. Parents make nuanced decisions which aim to preserve a sense of what is normal for them. Clinicians need to recognise the parental view, including where it may contrast with a medicalised or clinical view.

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unilateral hearing loss; shared decision making; paediatric; parent

Introduction

Unilateral hearing loss (UHL) in children may impact aspects of speech and language development, social-emotional development, academic performance and quality of life (Lieu 2018; Purcell et al. 2016; Roland et al. 2016) although there is variation in the extent of impact on children (e.g. Fitzpatrick et al. 2019). In England, children with UHL are typically identified through the National Health Service (NHS) newborn hearing-screening programme, the school entry hearing screen or via parental concern (Bamford, Uus, and Davis 2005; Bamford et al. 2007; Fortnum et al. 2016; Watkin and Baldwin 2012; Wood, Sutton, and Davis 2015). Following identification of UHL, treatment options available include hearing aid provision (Contralateral Routeing Of Signal (CROS) aid, behind the ear hearing aids, Bone Anchored Hearing Aids (BAHA) on softband) (Rohlfs et al. 2017) and other types of audiological intervention such as cochlear implants and bone-anchored hearings aids (Lieu 2013; Doshi et al. 2013; Hassepass et al. 2013), although cochlear implants and bone-anchored hearing aids are not routine intervention options in England. Modes of communication are also an important factor to consider and the subsequent need for Speech and Language Therapy is also available to help support children with hearing losses (Ching et al. 2018; Crowe, Fordham, et al. 2014).

There is little information on the effects of early intervention for UHL (Holstrum et al. 2008; Ross et al. 2008Appachi et al. 2017). Therefore the habilitation options presented to families are inconsistent (Strong et al. 2005; Yoshinaga-Itano et al. 2008) and likely to be decided at the service level or based on the preference of individual clinicians. Parents are left without standardised guidance from audiology services on how to manage their child's UHL.

We do not know how parents experience healthcare services for their children with UHL. Nor how they make decisions about interventions when the evidence base is limited and there are no best practice guidelines for clinicians. Grandpierre et al. (2018) explored parents' experiences of audiology service provision, looking at early experiences of hearing loss, technology and services. They also explored social experiences as well as the child's time in early education. The study reported parents often required more guidance and support in order to help their child through school in relation to decision making. Fitzpatrick et al. (2016) explored the experiences of parents of children with both mild and unilateral hearing loss to investigate the impact of these types of hearing losses. This highlighted their uncertainty around amplification, the importance of proactive parenting and the desire to meet other families in a similar position. This study did not separate unilateral hearing loss from mild bilateral hearing loss in its thematic analysis, with parents of both groups also report receiving conflicting information from professionals. Fitzpatrick, Durieux-Smith, and Whittingham (2010) report that amplification for unilateral losses was less common than for those with mild, bilateral loss. This implies that parental experiences of unilateral losses are different to those of bilateral, yet there is limited literature exploring this and whether there are differences in parental decision making. These findings warrant further investigation.

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Porter et al. (2018) reviewed the literature on how families (of children with hearing loss) make intervention decisions following diagnosis. They identified there were distinct stages to decision making: information exchange, deliberation, and implementation. This suggests that decision making is a linear, static process; however the needs of a child with hearing loss will change as they grow, such as school attendance, forming friendships and use of changing technologies. Crowe, Fordham, et al. (2014) surveyed parental decision making with regard to children with bilateral hearing loss and noted that information sources (friends, families and clinicians), the child's characteristics and the practicalities of communication strategies all influenced decision making. Similarly communication choices were examined in an American population (Decker and Vallotton 2016). However the challenge in unilateral losses is often that while oral/aural communication will be the preferred method, there are decisions to be made about different forms of amplification. This has not been comprehensively explored.

Although the studies described look at parental views towards having a child with a unilateral hearing loss and their experiences, they do not discuss the internal decisional processes that parents undertake but rather look at service processes and the outcomes of the hearing loss (e.g. Decker and Vallotton 2016). Mauldin (2019) discussed the need for understanding the complex social context around hearing losses and decision making. It is therefore important to consider the purpose of interventions but also the values and preferences that lead to decisions (Mauldin 2019). Family centred care is considered good practice in audiology (Scarinci et al., 2013) and is crucial in providing paediatric services, where family and audiologist partnership are required (Gravel and Mccaughey, 2004). It is vital to understand internal decision processes to provide family centred care (Gravel and Mccaughey, 2004).

The aim of this work was to investigate decision making processes of parents as their children with unilateral hearing loss develop, from initial diagnosis to school age.

Methods

Approach

We adopted inductive, qualitative methods to develop an understanding of parents' influences and decision making. Data were explored using the constant comparative approach, consistent with grounded theory method (Charmaz 2006). Grounded theory develops theory by comparing accounts from contrasting cases. In keeping with this approach, we devised an interview schedule from an informal review of the literature.

Data gathering

Participants were selected through theoretical sampling, to shed light on specific emerging concepts. Families were approached through three NHS clinical sites as well as through the Microtia UK charity. The interviews were carried out in participant's homes (or place of work for one parent) and followed a guide (see Table 1). Interviews lasted up to 1 hour and were conducted by AN and SH (audiologists with qualitative research training). The interview schedule was examined to see if it elicited relevant information during early interviews. No changes were considered to be needed and it was used across the data set with the open ended questions allowing for participants to lead discussion. Both AN & SH were closely supervised by HP (an experienced qualitative researcher). They were audio recorded and transcribed verbatim through an external transcription service. Families who did not speak English were also invited to participate and interpreter access was available if needed, however no participants requiring this came forward. The researcher 'memoed' the participants' non-verbal behaviours and emotional reactions to add richness to the data (Charmaz 2006).

Table 1. Interview guide.

- How did you go about making decisions?
- What were the effects of that?
- What was the main thing that happened?
- How did that influence your decision?
- What did you do/investigate to make your decisions?
- What was the result of your decisions?
- How do you feel about that decision now?

Data analysis

Each of the interview transcripts were independently coded and these codes were compared across the transcripts. The two data sets were initially coded by researchers AN and SH, followed by blind-coding with researcher HP to ensure consistency across the codes. These codes maintained a wide view of all possible theoretical directions and preferentially used 'in-vivo' codes to preserve the participants' language (Charmaz 2006) (summarising meaning statements using words from the participant to code them e.g. open coding). By exploring the operation, properties and dimensions of these codes the researcher condensed them into broader categories (axial coding). The relationships between these categories were explored to develop a framework of decision making. The category that explained the variation and was present in each transcript to explain variance is presented in the model below (selective coding).This model described variation within the data set. These findings were then compared to the wider literature.

These findings are based on two data sets. The first was gained from a population in Berkshire in 2016 and consist of accounts from eight families of nine children with unilateral hearing loss. In an effort to broaden this data set and check for additional important contrasting features we proceeded to gather a second data set from across the UK. The data were analysed initially to check manifest content and to compare data sets. The second data set was coded to summarise key meanings and recurrent themes within the data. These themes were compared across the two data sets. The emergent themes were agreed by all researchers to describe similar constructs and experience descriptions. The themes were then organised according to the paradigm of process (Strauss and Corbin, 1998) to develop a summary explanatory framework which accounted for variation within each theme (Figure 1). This framework summarises the key data from both data sets and explains how and why variation within themes occurs.

Ethics

National research ethics service approval was obtained through proportionate review. There were two episodes of data gathering, one in 2016 and the second in 2018. Favourable ethical opinion was granted by the East Midlands (15/EM/0387) and Newcastle and North Tyneside (18/NE/0154) Research Ethical Committees respectively.

Results

The children consisted of nine boys and thirteen girls. Eleven of the children were in primary and five in secondary education. An additional three were in nursery or playgroups, with three of the children under 1 years old and therefore not in any establishment. Sixteen of the twenty one interviews were conducted with only the mothers of these children and five were conducted with both parents present.

Participants

Families were approached through three NHS clinical sites; fifty six families were approached from a site based in South East England, thirty eight families from a West Midlands site and twenty two from a site in the South West of England. An advertisement also went out through the 'Microtia Mingle UK' Facebook group and Microtia UK website for families to directly contact the researcher. Eleven families participated in the study through the Microtia UK avenues.

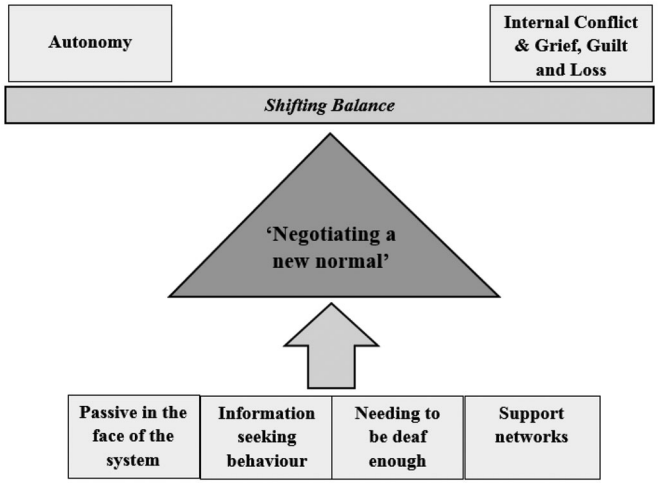

Figure 1. Framework of family decision making on management of unilateral hearing loss in children: Decision making is a balance of internal conflict and autonomy centring on a process of 'negotiating a new normal'.

Families that participated in this study were seen in their homes across the United Kingdom in the following counties: Berkshire, Bristol, Glasgow, Greater Manchester, South Wales, Sussex, West Midlands and Yorkshire. Socio-economic status varied between these locations from working class families to affluent professionals (determined by interview).

Families that were included had a child with unilateral hearing loss aged between four months and sixteen years old. This sample captured parental journeys through the healthcare and educational services and a wide range of intervention strategies. All families who participated in this study spoke English. In total twenty one families were interviewed with one family having two children who had a unilateral hearing loss (twenty two children altogether). Mothers participated in all interviews and were joined by fathers in six of the interviews (27%). The mean length of interviews was 52 minutes (range from 44 to 83 minutes).

All but one of the children were screened and identified through the newborn hearing screening programme (including referrals straight to Audiology departments for the children who had microtia), and one through the Health Visitor screening programme (which preceded newborn screening), suggesting congenital unilateral hearing loss. All parents have had professional contact with Audiologists and a Teacher of the Deaf (at various stages through their journey). All of the families have seen other health professionals ranging from Paediatricians, Ear, Nose and Throat consultants, maxillofacial surgeons and speech and language therapists. Out of the twenty two children, sixteen either wore a hearing aid, BAHA or BAHA on a soft band. Surgery was offered to the two children with conductive unilateral hearing loss and one of them took this up. There were eleven children with microtia, one of whom had gone through the ear reconstruction process with another in the process of obtaining a detachable prosthetic ear. For details of the participants, please see Table 2.

Due to the varied geographical locations of the families, levels of support from Audiology services ranged from local secondary NHS services to referrals to specialist and/or tertiary centres, particularly for microtia ear reconstruction. All parents have maintained mixed levels of contact with Audiology for routine hearing reviews and/or device support. Access to a Teacher of the Deaf varied dependent on local council funding. The

Table 2. Breakdown of participants.

Participant ID	Who was interviewed?	Age of Child?	Presence of Microtia?	Urban/suburban or rural setting	Hearing device worn?
1	Mother and Father	11 months	Yes	Urban	None at present
2	Mother	11 years	Yes	Urban	Yes
3	Mother	4 months	Yes	Rural	None at present
4	Mother and Father	5 months	Yes	Suburban	Yes
5	Mother	3 years	Yes	Urban	Yes
6	Mother	2 years	Yes	Urban	Yes
7	Mother	10 years	Yes	Urban	Yes
8	Mother and Father	13 years	Yes	Urban	Yes
9	Mother	8 years	Yes	Suburban	Yes
10	Mother and Father	7 years	Yes	Urban	Yes
11	Mother	9 years	Yes	Rural	Yes
12	Mother	3 years	No	Urban	Yes
13	Mother	7 years	No	Urban	Yes
14	Mother	6 years	No	Suburban	None at present
15	Mother	5 years	No	Suburban	Yes
16	Mother	13 years	No	Suburban	Yes
17	Mother and Father	13 years	No	Suburban	Yes
18		11 years	No	Suburban	None at present
19	Mother	7 years	No	Suburban	None at present
20	Mother	9 years	No	Suburban	Yes
21	Mother	16 years	No	Town	Yes
22	Mother	4 years	No	Town	None at present

availability of support groups ranged from a variety of charities and clubs in the family's home city, to none at all, requiring families to travel to other cities to access information or 'meet-up' events. All of the families with a child who has unilateral microtia have used the 'Microtia Mingle UK' Facebook page to varying levels.

The following section describes the core themes that parents reported to have influenced their decision making.

Findings

The core themes were organised into an explanatory framework (illustrated below – see Figure 1). This described key features of the process of decision making and followed the grounded theory approach to formulating explanatory frameworks (Strauss and Corbin 1998). This framework organises themes into stages in a process through which the decisions about a child's unilateral hearing loss are managed. The process is organised into themes referring to core beliefs, attitudes and existing circumstances that characterise the view point through which a decision is made. The core process is one of negotiating the 'new normal' e.g. the active process of adjusting from prototypical characteristics of 'normal' hearing to the functional hearing characteristics of their child. This involves a re-defining of 'normal' hearing behaviours, function and visual signifiers (e.g. the presence of a small pinna in microtia).

The negotiation of a 'new normal' forms the core category of these data, meeting the conditions for core category following Strauss and Corbin (1998) as the category that occurs in each case, a category that explains variation in subsequent expressed view or action and a category to which all other codes relate. In this case this refers to an active and iterative process of weighing up. The balance is between preserving the child's autonomy (including the importance of delaying intervention decisions until the child is old enough to make them themselves) against the internal conflict of the parents of judging the best course of action.

To protect the anonymity of participants we have not identified the quotations derived from interview.

'Negotiating a new normal'

The 'negotiating a new normal' was a process of reconciliation of parents' expectations of their child. This was characterised by guilt and a shift in perception which included a sense of loss of the expected typically hearing child.

'Normality' was a frequently described concept and as an active process on the part of families.

> She's grown up normally as all the other children. (ID2)

> We've always treated her like um, as normal, we've never, you know, she's never had any kind of special treatment (ID2)

The version of normality is influenced by what was usual for the family.

> It would almost be weird if we had another one and we didn't have to worry about hearing aid bands and things like that, you know what I mean? It's just, it's just, you know, it's just part of her now … it feels weird when she doesn't wear it. She looks naked without it (ID4)

Interestingly several participants comment on how the 'invisibility' of hearing loss is a reason to take up, or maintain hearing aid use. One mother shared she does not just use the hearing aid as a tool to improve her child's hearing, but also as a tool to make other people aware that she has hearing loss, believing that if people think she has a hearing loss they will be more understanding of her other behavioural needs, '*So I think a lot of people just see the hearing aid and are more acceptable of the odd things …' (ID15)*. This suggests a belief that in order for their child's needs to be recognised, a visual reminder is required.

'Internal conflict' and 'grief, guilt and loss'

These codes were linked closely to the evaluation of 'normality'. The internal conflict is the code that describes the constant revaluation of their decisions and actions.

> Have we done the right thing? (ID4)

> Oh gosh, you know, she's, what's she going to be restricted by and you know, looks-wise, what, what do people think (ID6)

The grief, guilt and loss theme is linked to this as a description of the emotional adjustment that parents undertake.

> It was a bit of a shock at the start, weren't it? It was a bit like, I wasn't really myself. (ID1)

Parents describe shock as being linked to grief and guilt.

> I was in the hospital for a week, crying, thinking that I'd done something. (ID1)

The sense of loss is associated with guilt and responsibility as illustrated below:

> He thought he'd done something. And I couldn't even pick her up because I just felt like I was responsible. (ID1)

Autonomy

'Autonomy' summarises the value placed upon the child as an individual with rights and values beyond their role as a person with hearing loss. This theme is the pre-existing value that families consistently describe.

The theme describes the families' preference for children to have rights to self-determination and to individualise their care. This applies to hearing devices in particular.

> We feel the best thing for her is to let her make her own choices. (ID1)

Similarly parents contextualise decisions around unilateral loss as influenced by a broader need to involve the child's view because:

> It's her life. (ID4)

These views influence the emphasis on respecting the child's choices with regards to hearing aids including removing hearing aids.

'Needing to be being deaf enough'

The code 'needing to be deaf enough' was used to summarise the questions parents asked themselves around credible access to care, including the use of devices. For most parents these decisions were based on assessing and weighing up the child's function and placing a limit around key functional goals.

> It's optional. If we feel that she needs one … um … if her speech or her balance, things like that, started. Not meeting her milestones … then we could look into getting a BAHA for her. (ID1)

Parents describe judging whether their child was 'deaf enough' for interventions based on feedback from clinicians.

> They [Audiology] probably thought that he would cope fine with the hearing that he's got, although directional sound would be an issue (ID3)

Linked to this are iterative decisions about continuing to use devices.

> I suppose the other concern is, if he gets an ear infection or glue ear or something, that affects his big ear, then we'd obviously want the backup, of having a hearing aid perhaps for his other ear. (ID3)

Where a child felt as though his hearing aid was stigmatising ('*marked him out*') this was interpreted by family as a legitimate reason for non-use. The functional impairment is not severe enough to be prioritised over social stigma. It appears that where children are not self-conscious about wearing hearing aids, or where the perceived benefit of hearing aids outweighs the cost of its appearance, children continue to wear them. When the child expresses self-consciousness, parents consider this an acceptable reason to stop use.

> If it's bothering you, just don't wear it. (ID2)

This suggests that parents consider the psychosocial impact of wearing a hearing aid on their child in deciding whether or not to continue this intervention.

Passive in the face of the system

Being 'in the system' is how parents describe their experience of NHS and education support services. Being in the system is the mechanism through which families obtain information and advice about their habilitation options. It primarily refers to Audiology services, Teacher of the Deaf support, medical consultations, and Speech and Language Therapy. The tone of encounters within the system is described as influenced by biomedical notions of deafness and hearing, with children categorised according to norms of hearing function. In doing so the family described their role as passive. This passivity is evident in the use of passive voice when describing the relationship with the service.

> I think with unilateral loss, there's a bit of a grey area where it's like, well, your child has got one good ear. (ID5)

Interactions with clinical services were frequently described as unhelpful, with a clear contrast between biomedical view and family view.

> The only thing I haven't liked in the whole process of finding out what it is and everything … we did go to see a consult, … and … I may have took it personal, I don't know, but I said to him … um … "Is this classed as a disability?" and he went, "Yes, yes, it is!" So, that kind of made me feel a bit like I didn't want to label it as that. I don't want to label her as disabled. If it means putting down that she's got, because to us she's the same as everybody else. It isn't a disability in that sense, unless she, unless she couldn't walk properly, like her balance was affected, or her speech was affected … she's the same as any other kid, the way she behaves and acts … So, to me, it's definitely not a disability at the minute, it's just purely a cosmetic thing for her. (ID1)

Or alternately clinical services were described as having no real insight or support to offer.

> No-one knows, no-one gives us any answers (ID1)

Parents descriptions of audiological care imply a sense of dismissal towards them and their children.

> She (audiologist) just wanted to know, basically just checked the ear over, basically. That's all she wanted to do … And we haven't really had anything since. (ID1)

The passive voice was used to describe encounters as in this case. This leads to a sense of passivity in the process.

> We came back and had to find out what the name was ourselves (ID9)

The majority of participants describe the Teacher of the Deaf as their most valued resource. Their role in liaising with their child and with the child's school about their hearing needs was described as 'invaluable'. One mother described how the Teacher of the Deaf has supported their child in her decision to try a hearing aid, '*Erm, I would have encouraged her but I wouldn't have been as authoritative in terms of I, you know I didn't know how much it might help her. I can't imagine only hearing through one ear and I can't imagine hearing through a hearing aid so I couldn't work out how much it might help to have a hearing aid suddenly after 10/11 years without erm. And also there were some things that I can say to her and she dismisses because I'm her mum but someone else can say and she'll, she'll you know think about it.' (ID8).* This demonstrates that the Teacher of the Deaf increases parents' knowledge of different strategies and influences their intervention choices.

Support networks and information seeking behaviour

Families describe gaining information not only from clinical services but from charity run and parent support groups.

> We've been really relying on the microtia group on Facebook. They really helped us make an informed decision on whether or not to treat it. (ID4)

These support networks provided an opportunity for social comparison.

> I was talking to her and she was saying that her son had gone through a similar phase at the same age. (ID7)

In this way they provide key information and a sense of perspective on what to expect.

> When I found them on uh Facebook, it was nice to know there was other people out there. But it was nice to speak to people or ask questions and somebody would respond. And it was like, "Oh, you could put your mind at rest about stuff. And or give you advice." (ID9)

Discussion

The decisions

Decision making is not a single event for these families. Decisions made ranged from waiting for the child to make their own decision in the future, to deciding to intervene with hearing aids (including BAHAS). Parents continuously cycle through a process that integrates information from their own observations, the guidance of professionals and their child's opinions. The dominant feature is the parents' iterative assessment, but this is shaped by the habilitation options that they perceive to have been offered to them. The influence of professional opinion may be strong enough for them to take up a particular intervention. However, their iterative assessment and the views of their child will dictate whether the intervention is maintained or stopped. This work represents an assessment of the decision making processes of parents who have children with unilateral hearing loss.

It illustrates the likely decisional and support needs of these families. The framework generated is at a sufficient level of abstraction to allow it to be related to the broader literature on decision making for children. For example, Lipstein, Brinkman, and Britto (2012) reviewed the literature the parent-child decision making processes across a range of medical treatments, showing parents wanted to include their child in the discussion. In relation to decision making for deaf children, not only those with unilateral hearing loss, parents reflect that they were led by professional advice, and were not given clear information about how their chosen intervention would impact on their lives (Fitzpatrick, Jacques, and Neuss 2011; Hardonk et al. 2010; Hyde, Punch, and Komesaroff 2010; Li, Bain, and Steinberg 2004; Ramsden et al. 2009).

We have modelled how parents of children with UHL make habilitation decisions. The decision making process made by families in this study highlights the phenomenon of a 'new normal'. There are various factors that contribute towards the negotiation of this new reality, such as the interactions with professionals, technology and schools which were also explored by Grandpierre et al. (2018). These factors and the mechanisms behind them identified the struggle to access information and services, leaving parents confused and lacking confidence in the health system. Similarities between this study and ours included barriers to services and support from professionals including schools. Although screening and diagnostic processes exist to identify hearing loss from an early age, it is the consistency in support that is required by parents in being able to make informed decisions for their child (Fitzpatrick et al. 2019). Decisions about unilateral hearing loss are not linear and they are a product of iterative assessments of their child's progress over time, as opposed to the often time dependent decisions of children with bilateral hearing loss, which are focussed on communication mode (Porter et al. 2018). The decision to provide any audiological intervention was dependent on the needs of their child, with a range of outcomes presented by the participants in this study (including hearing aid uptake and use, non use, watchful waiting, help-seeking from audiology and regular review or non help-seeking).

There was an overwhelming sense that parents felt support by their healthcare provision was inconsistent. It is important to note that this was not the case for all families involved in this study, but it was clear there was a lack of understanding, knowledge and effective communication between clinicians and parents. These mixed messages were also reported by Fitzpatrick et al. (2019). This lack of information was not unique to the participants of this study; Young et al. (2006) report that parents of children with hearing loss are not given information on all support options, especially where clinicians favour one mode over another. It is important that literature is accessible to parents in order to help with shared decision making processes, and support the provision of verbal information (Donald and Kelly-Campbell 2016). Parents were often tasked with seeking information from variety of sources, namely on the internet. However, it is clear that sorting through the plethora of information, quality websites are in short supply (Alamoudi and Hong 2015).

Participants' information sources and social support ranged from local and national services to online forums and websites. The role that support groups played was evident here, with the opportunity to build networks, but also for the comparison and discussion opportunities they provide. Research into parent to parent support for those who have children with hearing loss demonstrated the effective role this had in confidence, information sharing and advocacy for each other (Henderson, Johnson, and Moodie 2014). Lipstein, Brinkman, and Britto (2012) also commented on the several agencies that parents look to for support in decision making processes, including those of their community. Online support was evident in our study as a source of information, which can be an influential factor in parental experiences (Ziebland and Wyke 2012).

Our intention with this work is to build theory and understanding and we do not claim generalisability to every context. It is worth considering the nature of this UK population. We recruited families from across England, Wales and Scotland and from a range of urban, suburban and rural settings, reflective of the broader population. All our participants had access to care via the National Health Service. We include participants in this study from diverse socioeconomic backgrounds. A limitation is that all families were of White ethnicity. Our parent sample had access to 16+ education. The majority of the participants in this study were mothers, with only six fathers participating in joint parental interviews; there were no father only interviews in this study. This could be due to the nature of professions and availability amongst the participants and gender differences.

The trustworthiness of this research was enhanced by following a clear methodological approach and including double-blind coding processes. Findings were triangulated by parallel analysis. These processes were applied consistently across both data sets.

This work provides a theoretical framework for future work in paediatric audiology care. It informs clinicians about the perspective of families and their priorities to normalise their experience. Future intervention development and service delivery studies may benefit from this theory.

Conclusion

This study has illustrated the mechanisms behind parental decision making for children with unilateral hearing loss. Rigorous qualitative studies contribute vital insights into the processes of decision making and for an important part of the evidence base for clinical practice (Greenhalgh, Howick, and Maskrey 2014). This is an important contribution to understanding parent views and preferences (Legare et al. 2008). In particular it provides insight into the parental experience of 'negotiating a new normal' which occurs through weighing up the value of autonomy against the conflicting suggestions for actions gained from clinical sources and support networks. Understanding this internal conflict is important for clinicians to adapt their behaviours in ensuring shared decision making. In addition, decision making is iterative and changes over the child's life, so there is a need for clinical services to be responsive to the changing information and decisional needs over time, and the need to involve the child themselves once they are old enough.

Future directions

This work highlights the complex and iterative decision-making that families undertake. It is important that services acknowledge this process and include such participants to advise on service policies. In particular ensuring fully informed decision-making is a priority.

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