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A qualitative exploration of the assessment process to cochlear implantation for children with hearing loss

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ABSTRACT

Objective: To explore the process of paediatric cochlear implant assessment, from referral to implantation, from the perspective of parents, cochlear implant professionals, and through observations of clinics.

Design: Qualitative approach, using grounded theory methodology.

Study sample: Twelve families with children under 5 years with permanent hearing loss referred for a cochlear implant or received an implant in the past year, and six professionals who refer or assess children for cochlear implants. Data collection involved interviews and ethnographic observations of assessment clinics.

Results: The core theme derived from interview and observation data related to the work of the cochlear implant assessment for families. The relationship between the work generated by the assessment process and capacity of parents to do the work provides a model to examine access to early implantation, consistent with the Burden of Treatment theory. We identified variation in terms of workload, relating to factors such as a child's additional needs or number of appointments required, and in terms of capacity, relating to factors such as social circumstances or health literacy. Social, peer and professional support and information helped families manage the workload.

Conclusions: Findings have implications for delivery of paediatric cochlear implant services.

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Introduction

The UK National Newborn Hearing Screening Programme aims to identify children with permanent hearing loss at birth to enable development of age-appropriate language by school age (Wood et al. 2015). Up to 90% of children with severe/profound hearing loss are born to hearing parents (NDCS 2016). For children who do not benefit from conventional hearing aids, cochlear implants (CI) provide them with access to spoken language where this is the chosen communication mode. This group of children are the focus of the study.



For children with congenital hearing loss, earlier age of implantation is associated with improved communication outcomes (Ching et al. 2018; Dettman et al. 2021). For this reason, CI guidelines aim to minimise the time between identification of hearing loss and implantation to reduce the impact of auditory deprivation (Kral and Sharma 2012). Research to date has primarily focused on the relationship between child factors (age of implantation and cognition) and language outcomes for children using CIs. For children with congenital hearing loss, implantation before the age of 9 months was associated with better linguistic outcomes compared to children implanted after 9 months of age (Dettman et al. 2021; Karltorp et al. 2020). However, there is variation in the time taken from identification of hearing loss to implantation across children (Broomfield et al. 2013; Dettman et al. 2016) and it is therefore important to understand how and why the variation may arise, and to identify


whether there are factors along the pathway that are potentially amenable to intervention.

Research examining the pathway to cochlear implantation in children has typically examined factors that statistically predict the age of implantation. Factors implicated include socioeconomic status, family factors, child hearing and health factors, difficulties with decision making and health service factors. We review these in turn.

Socioeconomic status, typically measured through health insurance status or postcode, predicts later age of implantation in United States, Australian, and Canadian healthcare settings, with children from more socially disadvantaged families being implanted later (Armstrong et al. 2013; Dettman et al. 2016; Fitzpatrick, Ham, and Whittingham 2015; Fujiwara, Ishiyama, and Ishiyama 2022; Lester et al. 2011; Yang, Reilly, and Preciado 2018;), although this finding has not been observed in all studies (Chang et al. 2010; Cheung et al. 2023).

A range of parent and family factors have been identified as relevant. Yang, Reilly, and Preciado (2018) found the most common barrier to be “pragmatics”, covering domains such as ease of attending appointments, contacting clinics, taking time off work, childcare, and family needs. Armstrong et al (2013) identified parental difficulties with navigating the healthcare system and non-attendance at appointments, and Lester et al (2011) found “parental delays” were associated with later implantation for those implanted after age two years.

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Additional medical or complex needs are another important factor, where children with hearing loss and additional needs are more likely to receive their implant later than children without additional needs (Armstrong et al., 2013; Fitzpatrick, Ham, and Whittingham 2015). The reasons behind this are likely to be multifactorial and include the longer time to achieve audiological certainty than for typically developing children (Fitzpatrick et al. 2017; McCracken and Turner 2012), and that parents of children with complex clinical needs typically have more appointments, over a longer period of time, and experience greater levels of uncertainty (McCracken and Turner 2012).

Parental decision making has been examined qualitatively to explore what can help or hinder decision making, and therefore could contribute to time to implantation. Many parents find decision making for CI difficult (Hyde, Punch, and Komesaroff 2010), and poor information and lack of knowledge can hinder decision making (Hardonk et al. 2010). A study of Japanese parents found those who did not believe there was benefit of early implantation delayed their decision-making (Okubo, Takahashi, and Kai 2008).

Health service and system factors have been implicated where delayed referrals from health services are associated with later age of implantation (Dettman et al. 2016; Fitzpatrick, Ham, and Whittingham 2015; Lester et al. 2011). Within a wider context, health services face a growing challenge in allocating resources across increasingly complex populations with chronic, and often, multiple health conditions (May et al. 2014). Typically, this has resulted in health providers devolving more of the care and management of health conditions to patients (May et al. 2014). Little is known about the effect of this within paediatric CI services.

The research described implicates a range of relevant factors in a child's journey to cochlear implantation. There has been limited qualitative inquiry into the importance and role of these factors for parents during the CI assessment process, and to our knowledge no investigation within a UK paediatric context. Given the benefits of early cochlear implantation for optimising linguistic and overall communication outcomes (Ching et al. 2018), it is important to examine the processes associated with the patient journey from referral for implantation to surgery, from both professional and parent perspectives. By gaining a thorough understanding of the events, encounters and experiences that occur along the way, from a range of perspectives, it should be possible to identify areas for service improvement (Rapport et al. 2020).

We therefore aimed to answer the question: What is the process of paediatric CI assessment, from referral to implantation in a UK context, from the perspective of parents whose child has been referred for CI, from professionals involved in the CI process (referral and assessment) and from direct observations of parents and professionals in CI assessment clinics?

Materials and methods

Approach

Applied health research often requires a multi-method approach to data gathering so that a specific real-world problem is examined in different ways simultaneously (Shaw and Hiles 2017). In this case, we combined qualitative methods to provide an inductive model of the processes that influence clinical engagement with cochlear implantation. Ethnographic observations of clinic appointments and semi-structured interview data were combined using a grounded theory approach of constant comparison

(Strauss and Corbin 1990). Furthermore, we explored the process of cochlear implantation from two separate perspectives: parents/primary caregivers (hereafter referred to as 'parents') and professionals. The inclusion within the data set of both perspectives, alongside observations of the interactions between them provided a comprehensive investigation of this process, and explanatory and contextual information on how the process occurs.

Grounded theory is particularly well suited to analysing processes, such as health service structures and clinical interactions, with a focus on understanding and theorising relationships and linkages (Stillman 2006). It proposes an analysis approach based on comparing meanings within data sets (Charmaz 2006; Strauss and Corbin 1990). Firstly, researchers examine transcribed observations and interviews and break data into meaning statements (referred to as codes). These codes are linked together into categories that describe common patterns within the data set. Finally, grounded theory approaches move beyond other forms of constant comparison to propose frameworks or models that have potential to explain variation within the data set as a whole. To develop a model, categories are linked into a paradigm or framework that explains variance and is centred around the identification of a core category that occurs throughout the data set and in every case, explains variation within the data set, and to which all other categories are linked (Charmaz 2006; Strauss and Corbin 1990). Triangulation of perspectives within the overall data set contributes an opportunity to test the 'fittingness' of developing categorical frameworks in each data set (Wilson and Hutchinson 1991). In this case to examine the process of implantation we considered three data sets: parent interview data; professional interview data; observation of clinical encounters data.

We used semi-structured interviews with parents, and health and education professionals, shaped by the researchers' ability to recognise the pertinent topics and report in such a way that parents' stories and voices are accurately represented (Charmaz 2006; Strauss and Corbin 1990). In order to triangulate findings, we gathered a related data set of observations, where the researcher was present in CI assessment clinics at the Midlands Hearing Implant Programme Children's Service (MHIPCS) in the UK, and observed and recorded the interactions between parents and professionals relating to cochlear implantation in the clinical context (Hammersley and Atkinson 2007). These observations provided contextual and mechanistic information on the processes involved in implantation. The interview data were conceptualised with this contextual information and these observations provided topics to explore in interviews. As such this multi-method approach provided the basis for constant comparison of developing codes and categories in the data sets. Observational and interview data were compared to examine categories in each set. Categories that provided contextual descriptions and those that described perceptions and experiences were grouped and prioritised by researchers (first three authors) in accordance with grounded theory methods.

Rigour and reflexivity

We used a number of methods to ensure the rigour of our research. We were reflexive throughout the project, with two of the team experienced in working with paediatric CIs and all having a clinical background. We reflected throughout on our clinical roles and preconceptions we may have about the CI process. The researcher who conducted the interviews and observations, also an experienced qualitative researcher, did not interview or

observe parents or children or professionals that they had worked with clinically. We collected data from two different sources using two methods of data collection, which allowed us to compare and contrast data and triangulate our findings. Finally, three of the researchers were involved in coding and categorising the data, with all codes and the final framework agreed as a group.

Ethics

NHS National research ethical committee (19/SC/0137) was obtained on 02.05.19 and Health Research Authority approval on 29.05.19.

Recruitment and sampling

We focused our sampling of parents on key characteristics associated with age of hearing loss identification, through an evaluation of MHIPCS clinical data. Families were identified from the clinical database of the MHIPCS, and sent information inviting them to participate. The study was also advertised on social media and in the MHIPCS clinic. Initially we used snowballing sampling techniques, then moved to purposeful sampling as the analysis progressed.

Parents

The sample were parents of children under 5 years with permanent hearing loss identified through the newborn hearing screen, who were referred to MHIPCS for a CI by their local audiology centre, were going through the CI assessment process, or received an implant at MHIPCS within the past year.

We used purposeful sampling which involved deliberately selecting participants based on specific criteria to ensure a diverse sample of participants. We sampled for variation in the following key characteristics: whether the child had a disability; whether the child had complex medical concerns; range of geographical distance from the implant centre; whether the family had English as a second language. Twelve families were recruited (Table 1).

Professionals

The sample were CI professionals, and professionals who refer children for CIs, and/or were involved in the CI assessment process. The term “professionals” is used to refer to a range of

medical, allied health, education and social care professionals. We sampled professionals with variation in the following key characteristics: professional group; role in decision making process; years of experience. Six professionals were recruited (Table 2).

Consent was volunteered, face-to-face at the start of each interview and observation, before audio-recording. The researcher ensured the participants had full awareness of the purpose of the project, the procedures, analysis, data storage and potential outputs. Anonymity was protected through assigning aliases and identification numbers.

Qualitative interviews

Face to face semi-structured interviews were conducted in English, at a location acceptable to the participant. Interviews were carried out by the researcher (second author), with supervision from the third author, an experienced qualitative researcher. Interviews followed an interview guide developed by the research team, and explored the process of cochlear implantation, and the process of decision making (Supplemental Table 1). The researcher asked parents to describe in their own words their experiences, actions and decision making from identification of their child's hearing loss, up to cochlear implantation or the present date if they had not yet had CIs. For professionals, the researcher asked them to describe in their own words their experiences and thoughts on the decision-making process to cochlear implantation, and what helps or hinders time to implantation.

Interviews were participant-led in order to gain insight into the participant's perspective. Initial interviews consisted of open

Table 2. Professional participant details (some details have been amended or not reported to ensure participants are not identifiable).

Code	Professional role	Years of experience in role
PRO1	Clinical (Surgery, audiology or therapy)	10–20 years
PRO2	Clinical (Surgery, audiology or therapy)	10–20 years
PRO3	Non-clinical (Education or social care)	10–20 years
PRO4	Clinical (Surgery, audiology or therapy)	10–20 years
PRO5	Non-clinical (Education or social care)	0–5 years
PRO6	Clinical (Surgery, audiology or therapy)	5–10 years

Table 1. Parent participant details (some details have been amended or not reported to ensure participants are not identifiable).

Code	Relationship to child	Age band	Occupation	Ethnicity	Languages at home	Child age	CI status	Child disabilities & additional needs
PAR1	Mother	30–39	Teaching professional	White British	English	3y 9m	9m use	None
PAR2	Mother	30–39	Administration	White Slovakian	English/ Slovakian	2y 4m	8m use	None
PAR3a	Mother	30–39	Healthcare professional	White British	English	0y 3m	Assessment	None
PAR3b	Father	30–39	Retail worker	White British	English	0y 3m	Assessment	None
PAR4	Mother	30–39	Full time carer	White British	English	2y 1m	Assessment	Cerebral palsy, GDD
PAR5a	Mother	20–29	Retail worker	White British	English	1y 3m	Assessment	None
PAR5b	Father	20–29	Manual trades worker	White British	English	1y 3m	Assessment	None
PAR6	Mother	30–39	Parent	White British	English	1y 8m	6m use	None
PAR7	Mother	30–39	Healthcare professional	White British	English	2y 7m	Assessment	None
PAR8	Mother	30–39	Full time carer	Bangladeshi	English	1y 11m	Assessment	Genetic syndrome
PAR9	Mother	30–39	Parent	White British	English	4y 4m	7m use	None
PAR10	Mother	30–39	Healthcare professional	British Indian	English	0y 7m	Assessment	None
PAR11a	Mother	30–39	Parent	White British	English	1y 11m	Assessment	GDD
PAR11b	Father	30–39	Manual trades worker	White British	English	1y 11m	Assessment	GDD
PAR12	Mother	30–39	Parent	British Pakistani	English/ Mirpuri	5y 3m	12m use	GDD, physical disabilities

GDD: global developmental delay

questioning, asking participants to recall their experiences, with minimal influence from the researcher. Simultaneously with the interviews, constant comparative analysis continued, and subsequent interviews became more focused on themes that were identified (Charmaz 2006).

Interviews were audio-recorded and lasted around 30-60 minutes. The researcher also noted memos of non-verbal behaviours, environmental factors and emotional reactions during the interviews to provide detailed context to the data (Charmaz 2006).

Basic demographic information about the participants was collected to describe the participant sample. For parents, this included age and sex of the child, whether the child has any medical conditions or disability, geographical home location, participant's relationship to the child, age band of the participant, ethnicity (Ons.gov.uk 2021), primary language spoken at home, and the participant's occupation. For professionals, this included age and sex, job role and years' experience of working with CIs. For each interview, we noted the route through which parents were recruited.

Clinic observations

Observations were conducted during standard CI assessment clinics at the MHIPCS. There are a range of CI assessment clinics that families attend (e.g. audiology, diagnostic, therapy and ENT medical), and they all involve discussions and information sharing between families and professionals. Observations were arranged of clinic sessions where both the parent and professional consented to take part in the research. Five sessions were observed.

Following procedures of ethnography (Hammersley and Atkinson 2007) the researcher aimed to describe and explain the phenomena under investigation. The session was audio-recorded

and the encounters that occurred during the clinic session were observed. The researcher also took field notes either during the session or directly afterwards; this included documentation of the nature of the interactions, issues discussed, sequences of utterances, the meanings communicated and shared.

Data analysis

Grounded theory methods of constant comparison were used to analyse the interview data (Strauss and Corbin 1990). Initial analysis consisted of "open coding" of all utterances, and subsequently comparing codes through "axial coding" (where codes are condensed and linked together). The analysis process continued in parallel with data gathering, where findings guide the topics and direction of the interviews. The clinic observation data took the form of written descriptions and audio-recordings of the clinic encounters between parents and professionals. Initial themes and codes were derived from the data.

Axial codes formed the basis for comparison across data sets (parent and professional interview data; clinic observations) and we used abductive reasoning to explore the concepts fully, which involved comparing concepts from one data set (interviews) to another (observations). This led to a rich interpretation of the codes. By systematically comparing and framing the codes we identified the process to cochlear implantation and identified the systemic features that maintained the status quo.

The open coding was carried out by the second author. The third author coded a sub-sample of transcripts and interpretation was compared and discussed. The first, second and third authors examined the codes across all data sources and developed the axial codes together. These codes were used to identify key categories synthesised from the three data sources, which as a team we developed into a framework to describe the main features of the process to cochlear implantation (Figure 1).

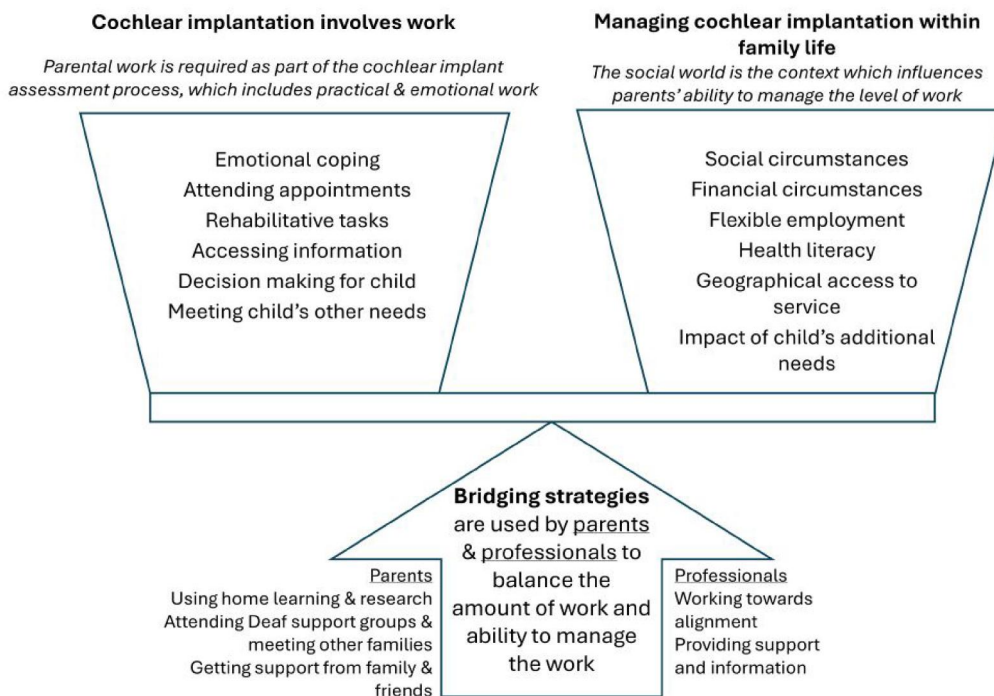


Figure 1. The process to cochlear implantation: the framework describes the relationship between the work parents are required to do as part of the assessment process, their ability to manage the work within the context of their own lives, and how this relationship between the medical and social world is managed by parents and with professionals.

Results

The phenomenon under investigation was the process of assessment to cochlear implantation. The final framework (Figure 1) describes the main features of the process. This includes the core category (the category through which all other categories relate), in this case “Cochlear implantation involves work”. It includes contextual factors in the category “Managing cochlear implantation within family life”. The linking category is named “Bridging strategies”.

Cochlear implantation involves work

The process of determining whether a CI is an appropriate option involved both practical and emotional work for parents, with the amount of work varying across different parents. The use of the term work is not to imply that the child or the child’s hearing loss is a burden, rather to refer to the practical and emotional tasks associated with the cochlear implantation process.

The CI assessment system involved a range of procedural activities that parents were required to do, which led to an ongoing process of balancing demands and resources. The practical work included attending appointments, working with their child on rehabilitative tasks, and parents’ own learning and researching information about deafness and CIs. The process involved giving parents a large amount of information, which could be overwhelming for some.

“My overall thoughts of the two appointments was that it was a lot of information to take in and I think it could easily overwhelm someone, especially someone who lives alone. The amount of information given became repetitive towards the end and I sensed that [parent] started to zone out slightly and become distracted more easily by her child.”
[Researcher field note, clinic observation number 2]

For many parents, the work required caused disruption to their lives such as the time commitment required for repeated assessments.

“That took a long time and lots of visits and lots of hearing tests and in the end I did get frustrated” (PAR7)

For all parents, the tasks associated with the process to cochlear implantation were viewed as necessary procedural process, but for some compared to homework.

“It is long, and a lot of work to do to help them, but it’s worth it, it’s worth every minute, every bit” (PAR6)

“... it can be difficult as a parent, because you feel like you’ve, you’ve almost like constantly got homework, like you can’t just enjoy your child” (PAR4)

In terms of emotions associated with the process, parents described joy, happiness and hope for what the CI may bring, and stress and worry around the operation itself and the irreversibility of the implant. The range of emotions depended on their stage in the process, their own emotional status and the unique circumstances they were in.

“.the thought of them actually having it we’re quite excited for” (PAR4)

Parents described the guilt and conflict arising from situations such as celebrating their newborn child while mourning what was lost, or wishing for their child’s hearing to deteriorate in the hope that this would speed up the CI.

“But nobody wants to be in a position, which we did feel like, where I wished she was deafer” (PAR7).

A significant task that some parents found physically and emotionally demanding was taking on the onus of making decisions on behalf of their child, and the learning and research required for this. Whether parents found decision making easy or difficult, all used similar strategies. This consisted of careful consideration, discussion, and weighing up of risks and benefits using their personal knowledge and experience alongside professionals’ opinions.

“I’m quite happy to follow doctor’s advice, you know, as long as I feel that it’s in his best interests” (PAR7)

At the heart of this was a desire to achieve the best for their children, and for some, feelings of fear and conflict that their child may one day regret the decisions made on their behalf.

“it’s a bit daunting to have like these options in front of you ... well what’s best now, they might not like” (PAR4)

Parents of children with additional needs often had extra practical work associated with managing their child’s medical condition, such as further medical appointments. The decisions around cochlear implantation also presented an additional layer of challenge in the context of uncertainty, even less predictable outcomes and additional risks.

“Because the fluid on his brain is not a good thing, now it’s like, do we risk it, is it worth the risk?” (PAR11)

Managing cochlear implantation within family life

This category related to the contextual factors that influenced parents’ ability to manage the work. These included their financial and social situations, their geographical location, their health literacy, and their child’s health. Many parents spoke at length of the various adaptations they had made to enable the assessment process and the impact this had on their paid and unpaid employment.

“Sometimes we’re up at half past 4 aren’t we? To get to [name of city] for like 9 o’clock” (PAR9)

“It’s kind of having to take leave ... it’s difficult” (PAR10)

Parents’ other caring responsibilities and social circumstances influenced their ability to engage with the work.

“he needs that one-to-one isn’t it, and I don’t have that time to be honest, like I’ve got four children” (PAR12)

Parents with high levels of health literacy had the skills and ability to understand and work with the process. In this example, the professional was discussing with the parent the arrangements for surgery; the parent disclosed that they are a health professional and therefore trust and understand the process.

Parent: “Yeah, I’m a nurse, so I’m quite ...”

Professional: “Oh you’re a nurse?”

Parent: “Yeah, which doesn’t [both laugh], yeah, so I get it.”

Professional: “Yeah.”

Parent: “Totally, and I’m totally onboard with whatever, as long as they’re happy with him I’m happy.”

(Quote from clinic observation 3)

For parents of children with additional needs, they described not only the difficulty of carrying out tasks needed for the CI assessment but dealing with the responsibility of other major and complex tasks to facilitate their child’s development and

health. This highlighted a clash of expectations of the child's function.

"I've got to try and get [name of child] to learn something, which in their situation has been quite difficult at the best of times" (PAR4)

Here the parent described the clinical priorities as mechanistic, with clinical processes dominating over the child's individual needs.

"he's fighting with his health as well, you know, just expecting him to be a machine, he's not" (PAR12)

Bridging strategies

To manage the emotional and practical workload associated with the assessment process, within the context of families' own lives, parents and professionals used a range of strategies. We term these "bridging strategies" to reflect that they can help families bridge the medical and life world. Strategies included using information given by the clinic as well as seeking information from other sources such as the internet and charities, in some cases to translate clinic information into a more understandable format. Many parents implied information based on experience was more trustworthy as it reflected real life. The importance of using factual information was also emphasised, whether gained from healthcare professionals or from personal research. Information provision and communication from professionals had a large influence on parents and how they felt moving through the process. For the majority the communication was described positively with professionals providing it described as being supportive, inclusive and understanding.

"You could ask them questions, no matter how stupid it was, they'd give you the answer" (PAR9)"

Support from partners, other family members and friends was vital, as was meeting other parents who were in the same situation.

"we've met, what, four or five more parents with little 'uns like [child's name] and we feel more at ease now" (PAR9)

Professionals provided helpful support. In particular, the support from teachers of the deaf who visited families at home was described as invaluable.

"teacher of the deaf, she helped us out with a lot of decision making or, you know, just basically giving us more experience, information" (PAR6)

These range of strategies allowed families to cope with the work and translate their concerns and personal context into decisions and actions.

Professionals were working to align the workload to parents' individual circumstances. They recognised the parental work that is required as part the CI assessment process, and that to achieve good clinical outcomes with a CI requires parents to undertake significant work and effort. In fact, the term "work" was used many times by most professionals during the interviews not just in terms of the implant assessment but also in terms of parenting more generally.

"I mean it can change everything provided you work with it" (PRO1)

"we need to work hard at making them listen, learn, attend, play, teach them, read them books, all the things that all children need" (PRO2)

Professionals were aware that parents were from a range of backgrounds and situations which impacted differently on their

ability both to go through the assessment process and to manage the CI post-surgery to achieve the best outcomes. They described a range of factors that impact on parents' ability to do the required work of the healthcare system, including emotional coping, the impact of a child's additional needs, social circumstances, finance, practicalities, cultural barriers and health literacy of families.

"if they've got additional health conditions they have to prioritise life over an operation" (PRO3)

"I know it can be difficult for those families who where there is a single mum, or where dad is, has to be at work, and therefore mum is without a car for instance" (PRO4)

There were challenges working towards alignment in some cases. Alignment was challenged where the expectation of the health service and the family's ability to do the work or understanding of the work did not match up.

"they will not work with the child and they will not work with us, so the outcomes will be not as good there" (PRO1)

This illustrated the tensions in the professional role between aspiration towards an outcome and managing the reality of life circumstances. The professional perspective provided valuable context to interpret parents' views of the workload that was devolved to them.

From the parents' perspectives, their interactions and relationships with the healthcare system and professionals influenced their experience of the process, with positive and negative conclusions. Parents described alignment between their perspectives and the approach of the professionals.

"They're very good at being aware of what your expectations are" (PAR7)

Despite an overall expression of appreciation, parents at times articulated feelings of anger, frustration and scepticism about the process.

"My frustration was everyone's got the time, everyone's quite relaxed, but my child is not hearing" (PAR2)

Discussion

Workload associated with cochlear implants

We have developed a framework of the process from referral to cochlear implantation. The core category that explained the CI assessment process was the work involved for families. This work included the task driven work related to healthcare services and the emotional coping of parents around their child's newly identified hearing loss and the potential of CIs. Professionals had insight and recognised the work associated with the assessment process. Parents needed support to do the work and learn the processes.

There are a number of strengths to our study. Recognising the influence of our own backgrounds, particularly our shared clinical expertise, we remained vigilant not to inadvertently steer the data towards a solely clinical perspective. Instead, we prioritised the viewpoints of parents, acknowledging their unique experiences and insights into the care process. We triangulated our findings through integration of multiple methods and data sources, and we analysed collaboratively using constant comparison of findings and abductive reasoning to refine our understanding.

In terms of fittingness, our findings are consistent with the Burden of Treatment theory (May et al. 2014) which characterises an individual's burden of living with and managing a health condition as a balance between the work generated by healthcare systems and the capacity of people and their social networks to do the required work. This theory has been examined in a range of adult health conditions (Gallacher et al. 2011, 2018; Spencer-Bonilla et al. 2021) and also applied to caring for children with complex care needs (Page et al. 2020). It predicts that when the work becomes excessive or burdensome, adherence to treatment reduces. Within the context of our study, all children received a CI, so we consider adherence in this context to relate to the degree of parental engagement with the process of assessment rather than whether the child did or did not receive a CI. We propose that it is a useful theory to examine the process to cochlear implantation, and beyond, as it takes account of the fact that the work involved will vary across families, that there is varying ability of families to engage with and perform the work, and that there is variation in the extent of networks that families have to support them through the process. Rather than consider independent factors, it considers their inter-relationships and the context in which they occur.

Not all parents found the work excessive, but there were examples from our data where the work became burdensome, such as being overwhelmed with information, feeling like there was a lack of practical support, feeling like the number of hearing tests was excessive or having difficulties carrying out therapy for their child with additional needs (Supplemental Table 2). The theory predicts that for those where the workload becomes burdensome, it will take longer to achieve, for example, through non-attendance at appointments, delays in making a decision, or non-completion of required rehabilitative tasks, leading to delays in implantation as described in the literature (Armstrong et al. 2013; Hardonk et al. 2010; Yang, Reilly, and Preciado 2018).

Parents recognised the work is a core and necessary part of the process to cochlear implantation. In that respect our findings also resonate with the research of Mauldin (2016) in her ethnographic study of a CI centre in the US. She developed the concept of “ambivalent medicalisation” to describe the tension between the potential for CIs to allow deaf children to develop spoken language and the associated work required of parents, particularly post-implantation therapy. She identified however that the work requires and provides hope for parents.

The social and clinical context

The influence of the social context of families on their journey through the assessment process was a key finding. Socioeconomic factors such as lack of financial resources and low health literacy were identified as contributors to the challenges families face during the assessment process. These factors aligned with the broader concepts of social determinants of health (Braveman and Gottlieb 2014; Schuh and Bush 2021). Our data highlighted how societal inequalities can shape interactions with healthcare systems, and mechanisms by which inequalities could arise through the assessment process.

The medical complexity of the child was an important contextual factor. Parents in our data described how the assessment process was more involved due to their child's complex needs, consistent with reports elsewhere (Archbold et al. 2015; Jethanamest and Choudhury 2019). They also described the impact of managing their child's complex needs on their engagement with the assessment process, as well as the challenges and

frustrations of not always meeting professional expectations for their child. These findings were consistent with the physical and emotional theme identified in the review by Whicker, Muñoz, and Nelson (2019) on parent experiences of caring for deaf children with disabilities.

Recommendations for paediatric cochlear implant care

Our research revealed insights into the strategies parents use to bridge the social and medical world. Services could examine how they can facilitate these within their local context. Parents highly valued the information and support they received from other parents of deaf children and emphasised the importance of their own family and social networks. These findings were consistent with research examining the benefits of peer and social support for families of deaf children (Henderson, Johnson, and Moodie 2014; Poon and Zaidman-Zait 2014) and are an important component of early intervention provision (Moeller et al. 2013). Professionals such as qualified Teachers of the Deaf who support families in the home were also highly valued by parents.

Balancing a parents' workload against their ability to do the healthcare work is the aim of “minimally disruptive medicine” (May, Montori, and Mair 2009) and is a principle that could guide paediatric cochlear implant services to become more family centred. Our framework could be a useful tool for services to examine their local processes and determine strategies to minimise patient workload for different patient groups, including children with complex needs. We recommend that services routinely evaluate their age of implantation against clinically-held socioeconomic and demographic data to identify any potential inequalities in access to early implantation. Services should also consider:

The pace and level of information sharing:

- Information provided in a variety of formats (visual, verbal, written), translated as required.
- Information provided based on parent and family experiences.
- Information shared at the pace of the parent, repeated as required, taking care not to overload.
- Adequate communication between professionals so parents are not responsible for this.

The frequency and timing of appointments:

- Flexibility around timing of appointments, including bringing multiple appointments together.
- Ability to schedule surgery during school holidays.
- Allowing extended family members to be included in appointments.

The location and mode of appointments:

- Ability to offer virtual, telephone and group appointments as appropriate.
- Arrangements for assessment tasks to be carried out locally where possible and preferable.
- Consistency of clinicians to build parents' confidence and trust.

Knowledge about local and national support networks:

- Information provided on local peer support groups and expert patients.

Communication with local hearing services:

- Colleagues outside the CI team kept up to date and trained to support families locally.
- Good relationships with local Teachers of the Deaf so they can support parents appropriately.
- Access to expert patients and mentors so local services can learn from those with lived experience.

Limitations and recommendations for future research

Given the qualitative nature of our study, we acknowledge that our findings may not be universally applicable but rather specific to the UK context from which they were derived. They are also specific to hearing parents and professionals as we did not include perspectives from Deaf parents or members of Deaf communities. Future research could focus on developing measures to assess family experience of cochlear implant services.

Conclusions

The cochlear implantation assessment process generates significant work, which varies across children and their families. The ability of parents to manage the work also varies significantly. Recognising the treatment related burdens of the cochlear implant assessment process and understanding the specific barriers faced by families allows healthcare services to improve access and enhance patient-centred care.

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