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DEAF CHILDREN'S MENTAL HEALTH DIFFICULTIES: EXPLORING EXPERIENCE AND FACTORS ASSOCIATED WITH THE DIFFICULTIES EXPERIENCED BY DEAF CHILDREN

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Summary of the Major Research Project

Section A presents a systematic literature review of the empirical research of the risk factors and underlying mechanisms associated with mental health difficulties in deaf children. Twenty-five studies were identified from the systematic search. The prevalence of mental health difficulties in deaf children were outlined. Findings were synthesised and grouped under parents and deaf children to explore their differing perspectives. Risk factors include rehabilitation, relationship difficulties and sociodemographic variables. A critical evaluation of the studies is discussed, and the clinical and research implications are considered.

Section B presents a qualitative study exploring the experience of hearing parents of a deaf child with mental health difficulties. Seven parents were interviewed and analysed using interpretative phenomenological analysis. Three super ordinate themes and accompanying subthemes capturing the experiences of the participants were identified. The superordinate themes are: “deafness as a voyage”, “living with uncertainty” and “parenting on another level”. Findings are discussed in the context of existing literature. Clinical and research implications are considered.

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MAJOR RESEARCH PROJECT

SECTION A: LITERATURE REVIEW

What risk factors and underlying mechanisms are associated with deaf children's mental health difficulties

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Abstract

Background and aims: Several studies have established that deaf children are more likely to experience mental health difficulties compared to their hearing peers. The most recent review on the mental health needs of deaf children was conducted in 2013. Some risk factors were identified, but these were largely rehabilitation-related. This review aims to build on the 2013 review and identify other potential risk factors and their pathways.

Methods: A systematic search found 25 studies from PsycInfo, PubMed, ASSIA, MEDLINE, and Web of Science. Findings were synthesised and grouped under parents and deaf children to explore their differing perspectives. Several themes were identified under each group.

Synthesis and discussion: Deaf children demonstrated higher levels of difficulties when compared to hearing peers, although with greater variations in the deaf sample. Rehabilitation-related factors emerged as the main theme for parents whereas, for deaf children, risk factors related to relationship difficulties emerged. Only one paper explored the possible underlying reasons for the individual differences in the deaf sample. Limitations, clinical and research implications are discussed.

Conclusions: The findings have shifted slightly from the previous review in relation to the variables used to measure mental health difficulties in deaf children. The underlying mechanisms are still lacking and these need to be to be investigated to understand individual differences in the deaf samples.

Keywords: Deaf children; adolescents; mental health difficulties; risk factors.

Introduction

Definition of childhood deafness

Three in every thousand new-borns are deaf (Johnston 2006). It is thought acquired deafness will affect three per thousand children through environmental or medical issues (Schrepfer & Schacht, 2017). Degrees of deafness are typically expressed in decibels (dB); it can be described as mild (21db – 40db hearing loss), moderate (41db-70db), severe (71db to 95db) or profound (95db and above) (Smith et al., 2005). Classifications are also made according to age of onset (pre or post lingual), aetiology (whether deafness is genetic), and if genetic, whether it is syndromic (additional physical features such as blindness), or non-syndromic and whether deafness is bilateral or unilateral (Porter et al. 2021).

The impact of the diagnosis

Ninety - 95% of deaf children are born to hearing parents (UK Disability Resource Centre, 2018) and most of these families have not encountered any deaf individuals before the birth of their deaf child. This lack of reference experiences may lead to distress in hearing parents (Young & Tattersall, 2007; NDCS, (2016). Consequently, parents may feel as if they have lost their ‘perfect child’ and expected dreams (Paget, 1983; Kampfe, 1989). According to grief theory, they move through several stages of bereavement. As their child is still present, the parents’ grief can be described as ambiguous loss (Boss & Yeat, 2014). With ambiguous loss, grief may be disenfranchised by professionals due to their impatience with ambiguity. One example of this is that parents face many decisions after the diagnosis and are usually pushed to make quick decisions, such as whether to implant their deaf child and which communication mode to use (Decker et al., 2012). They may also feel overwhelmed by the need to acquire complex knowledge to meet their child’s unique needs. Parents must make crucial decisions about devices, modes of communication, and education (Porter et al., 2018). These decisions may be made increasingly difficult due to conflicting suggestions from professionals because of disparate perspectives about the meaning of deafness (Glover, 2003). These decisions have long term implications for their child’s language, cognitive, social and emotional development (Young & Tattersall, 2007; Hall, Levin & Anderson, 2017; Gulati, 2019). Difficulties in one or more of these will affect a deaf child’s progress. All of this, including having a deaf child, can contribute to higher levels of stress in families.

Theories of parents’ experience of deafness

A few theories have been employed to describe parents’ experiences of raising a deaf child. They are the following: chronic grief by Kurzer-White and Luterman (2003); maternal-child interaction theories as employed by Howes (2006), and the parental stress and adjustment theories (Young and Tattersall, 2007). The current findings across the literature are mixed; some hearing parents often described the early experience of raising a deaf child negatively whereas some hearing parents value the early diagnosis and intervention as it gives them some hope that their child can be “fixed” by using a hearing device (Flaherty, 2015, p. 73). Kurzer-White and Luterman (2003) suggested that hearing parents’ initial grief can be re-triggered due to witnessing delays in their deaf child’s development compared to their hearing siblings and peers. Several studies have found some disrupted and reduced interactions between hearing mothers and their deaf child when compared to hearing mothers and their hearing child (Rinaldi et al., 2013) and deaf mothers and their deaf child (Beatrijs et al., 2019). One aspect of disrupted maternal-child interactions is related to parental attitude towards deafness and this has been found to affect attachment development in deaf children (Sealy, McMahon & Sweller, 2023).

Several studies have demonstrated that hearing parents of a deaf child are more likely to exhibit higher levels of stress and adjustment difficulties (Zaidman-Zait & Most, 2005; Quittner et al., 2010). Several factors have been explored in context of parenting stress and these include income (Jean et al., 2018), higher age of diagnosis (Chen et al., 2013), extent of hearing loss (Pipp-Siegel et al., 2002), communication and language abilities (Stikaet et al., 2015), communication barrier (Quittner et al., 2010) and perceived social support (Park & Yoon, 2018). The studies have yet to explore potential mechanisms for understanding how these predictors operate to influence parenting stress and adjustment difficulties.

By contrast, deaf parents of deaf children are usually happy with their child's diagnosis (Goldin-Meadow & Mayberry, 2001). Deaf parents have the resources and life experience to make the best possible choices about their deaf child's future (Goldin-Meadow & Mayberry, 2001). In addition, deaf children from deaf families tend to do as well as their hearing peers in terms of language, cognitive, and social skills (Macdonald et al., 2018).

Constructions of deafness

The medical model.

Historically, the construction of deafness has been medicalised and this reductionist approach to deafness was dominant for many years. The medical model constructs deafness as a pathological defect that needs to be treated or cured (Power, 2005). Examples of treatment are cochlear implants and speech therapy with a view to assimilating the deaf person into hearing society. Speech and lip-reading skills are reinforced as many professionals believe that these encourage language and cognitive development in deaf children (Humphries et al., 2017; Humphries et al., 2022). Some studies have demonstrated that more support is given to families opting for implants compared to those who do not (Svirsky et al., 2000).

The social model of deafness.

The social model of deafness derives from the social model of disability. It views deafness as a difference rather than an illness. However, it also explains the disablement of deaf people in terms of their being second language users having reduced access to the majority language (McKee, 2011). The model highlights barriers, attitudes or exclusions that disable people with differences. One example is when a deaf person is unable to access information during their doctor's appointment. The surgery is disabling the deaf person by not providing a British Sign Language interpreter.

The cultural-linguistic model of deafness.

Many culturally Deaf people reject the medical model because they do not see themselves as disabled (Ladd, 2003). Deaf people have described the medical model as oppressive and reductive because it fails to acknowledge the importance of language, culture, and collective identity (Ferndale, 2016; Ladd, 2003). Culturally Deaf people often have very positive attitudes toward their deafness, seeing themselves as part of a distinct cultural community sharing common values and identity (Padden, 1980). The "cultural model" views deafness as a condition to be understood and preserved (Arnos *et al*., 1991). It is used to describe their identification as a distinct cultural group with their own beliefs, language, and needs.

The medical model and parents' early experience of deafness.

The first experience of deafness, for the parents, is the diagnosis itself and finding the degree of deafness. The initial experience to deafness is rooted in the medical model of deafness. Reagan (1995) suggests that this medical or hearing view of deafness is concerned almost exclusively with the audiological features of deafness and as a result emphasises what a deaf person cannot do. This is supported by a finding that the organisations, structures, and professionals' attitudes that the families often encounter perceive deafness negatively (Terry, 2023). Consequently, the parents' experience of having a deaf child may be akin to recovering from something that has been damaged (Lane, 1992). In order to recover from the diagnosis, many hearing parents of a deaf child may opt for oral communication and cochlear implants due to the hearing parents' beliefs, values and attitudes that are ingrained in the medical model. This implies that most hearing parents are exposed largely to a medical model of deafness and may not be presented or actively seek out for information about the social, cultural and linguistic life of the deaf community.

Difficulties deaf children may face daily

As these parents have not met deaf people in the past, hearing parents may lack the knowledge and experience to nurture their deaf child's unique needs due to inaccurate information received from professionals (Kushalnagar, Mathur, Moreland, Napoli, Osterling, Padden & Rathmann, 2010). It is possible these families will face significant challenges in parent-child interactions. Chronic lack of accessible communication with hearing parents is a common childhood trauma reported by deaf adults (Anderson et al., 2016). Less than 8% of deaf children use natural sign language in fluent and bidirectional conversations (Hall, Smith, Sutter, DeWindt & Dye, 2018). These means that most deaf children risk not developing a native first language foundation in either spoken or sign language. Additionally, in an orally dominant environment, a deaf child's access to incidental learning at home and school is often limited (Calderon & Greenberg, 2003). This limited access may be due to communication difficulties or because the child's unique needs are not addressed

(Bat-Chava, Martin, & Kosciw, 2005; Howes, 2006). Communication difficulties can affect how deaf children acquire social knowledge (Baron-Cohen, Tager-Flusberg, & Lombardo, 2013). This then increases the likelihood that problems regarding the theory of the mind, abstract thinking, and problem-solving skills will emerge (Hall & Snodden, 2019). Academic achievement, the formation of peer relationships, and the development of a healthy self-esteem may also be affected (Hall, Hall & Caelli, 2019).

Previous review of mental health difficulties in deaf children

The most recent review of the literature by Theunissen et al. (2014) was completed in 2013. Thirty-five papers published between 1945 and 2013 were reviewed, of which six were written by the review's author. The inclusion criteria were broad to gather as many papers as possible on this under researched field. The papers were grouped based on the study samples: a community-based sample, children attending special schools' sample and children with cochlear implants (CI) samples. Unfortunately, the studies were not critically assessed, preventing an accurate assessment of their quality.

The review suggested that deaf children are more likely to exhibit higher levels of externalising and internalising behaviours compared to their hearing peers. The prevalence rate was vague, and many papers did not report the exact rate. The risk factors associated with higher levels of difficulties were grouped into four domains: (1) type of hearing device, (2) auditory and medical factors, (3) communication and intellectual factors, and (4) sociodemographic factors. A summary for each group is presented in Table 1 below:

Table 1
A summary of the review

Group number	Findings
1	The results are very mixed with some results showing no difference between deaf children with CI and hearing aids (HA). Other studies, however, established that deaf children with CI had fewer difficulties compared to deaf children with hearing aids.
2	The severity of hearing loss is not related to higher levels of difficulty experienced by deaf children. The age of detection and intervention were each more significant factors related to mental health difficulties.
3	Greater language and speech skills were associated with fewer difficulties. Several studies have also demonstrated that children who use sign language are at greater risk of difficulties compared to those who choose to communicate orally. However, one paper demonstrated that if deaf children have good communication skills regardless of the modality of communication (sign language or speech) they are less likely to experience psychological distress. This paper also included deaf children born to deaf parents.
4	Many of the findings in this section are comparable to the hearing population, such as age, gender, and social economic status (SES).

The review highlighted the need for further investigation into difficulties experienced by deaf children as well as a wider range of associated risk factors. Research areas could include cultural identity, attachment, and parent-child interactions. Apart from a need for longitudinal studies, no other recommendations for future research were made by the authors.

Importantly, none of the underlying mechanisms were explored and discussed in the review. A recommendation was made by Moeller (2007) for researchers to identify and explain the underlying processes in deaf children, to give an insight into why some deaf children may experience difficulties when others do not.

Rationale and scope of the current review

It is ten years since the last review. A further review is needed to investigate whether the research landscape has changed since then. The 2013 review suggested exploring cultural and relational variables and how these influence deaf children's mental health difficulties. It may also be that more recent papers have explored underlying mechanisms related to deaf children being at higher risk of developing psychological distress. Therefore, papers after 2013 are gathered for this review.

Research Questions

As described above, deaf children face various difficulties in their everyday life. These difficulties increase the probability that they will develop mental health issues. The present review in table 2 aims to ask the following:

Table 2

Research questions

1	What does the relevant research posit about mental health needs in deaf children?
2	What do parents think about the risk factors related to their deaf child's mental health difficulties?
3	What do deaf children think about the risk factors related to their mental health difficulties?
4	What does the relevant research suggest about the underlying mechanisms that are connected to the risk factors?

Methodology

Five online databases were used to search for literature from 2013 to the present: PsycInfo, PubMed, ASSIA, MEDLINE, and Web of Science. The terms that were used in the search are outlined in Table 3.

Table 3

Search Terms

Terms related to young children and adolescents		Terms related to mental health difficulties		Terms related to deafness
adolescen*		mental*		deaf*
OR		OR		OR
young child*	AND	emotion*	AND	hearing loss
OR		OR		OR
you*		distress*		hard of hearing
OR		OR		OR
child*		depress*		hearing impair*
OR		OR		
teen*		anxi*		
OR		OR		
student*		behavio*		
		OR		
		psycholog*		
		OR		
		psychiatr*		

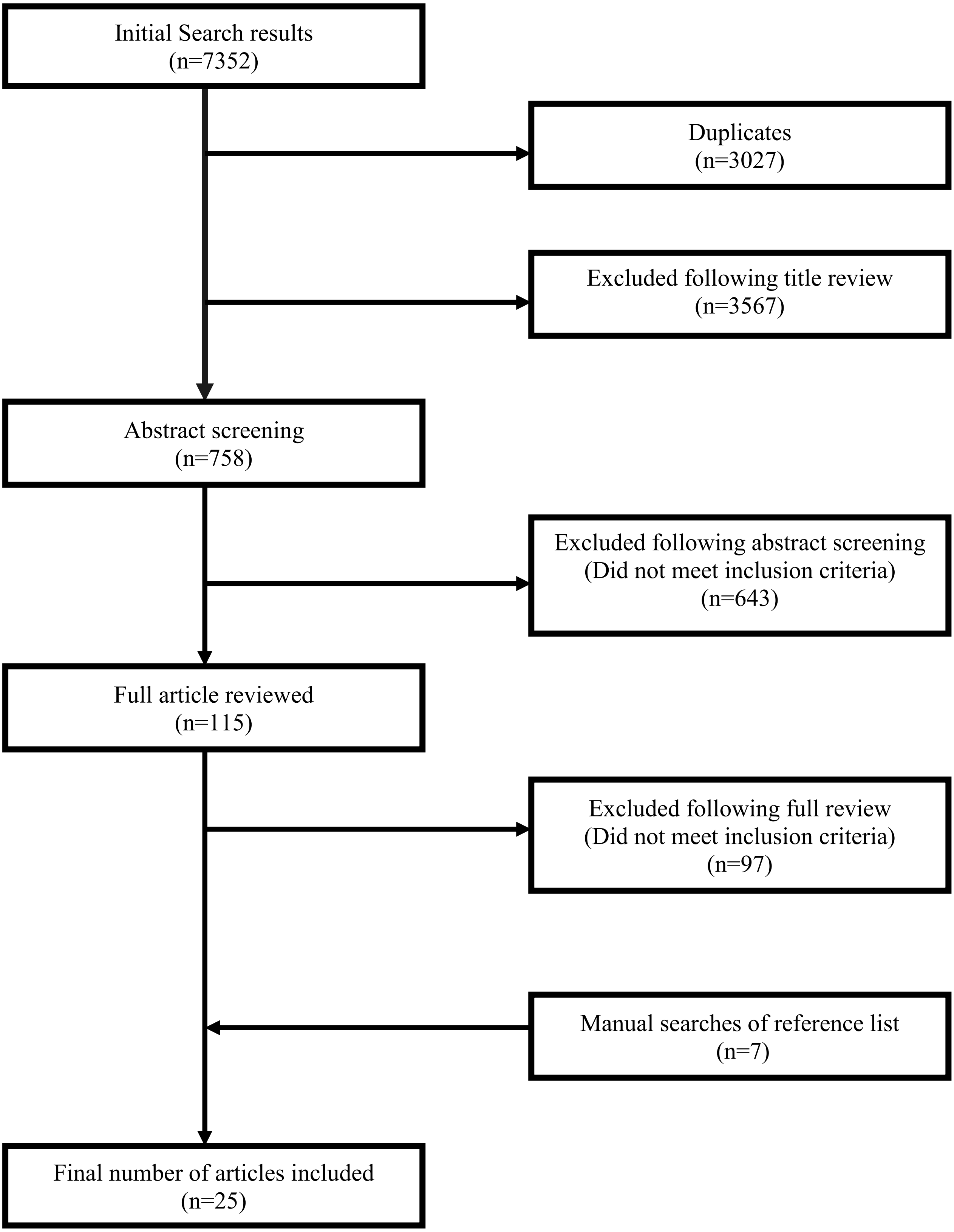
To locate other relevant papers, the same terms were used to search Google Scholar and the references it generated. 7325 papers were found in the initial search process, as illustrated by Figure 1. Some of them were removed based on precise criteria. The eligibility criteria are presented in Table 4.

Table 4
Eligibility criteria

Inclusion criteria	Exclusion criteria
Participants up to 18 years	Participants with severe mental health difficulties, i.e. psychotics and inpatient samples
At least 25dB of deafness	Papers not written in English
Subject's behavioural or/and emotional difficulties are scrutinised	Theses written by PhD students
Factors that contributed to behavioural and/or emotional difficulties are being investigated	

As a result, twenty-five papers were found. Figure 1 provides a visual flowchart of the literature search strategy.

Figure 1 presents an adapted PRIMSA flow diagram of literature search.



Results

Structure of the review

In the interest of readability each study is assigned a number within the study summary table (Table 5). The quality assessment criteria devised by Kmet et al. (2004; Appendix A) were also used to score the quality of each study (Appendix B).

Kmet et al. (2004) described how their quality assessment aimed to capture key quality indicators for studies that are quantitative in nature. Fourteen items were developed to appraise the internal validity of each study. The scoring of the items depended on whether specific criteria were met (yes = 2 points, partial = 1 point, and no = 0 point). Items that were not applicable to a particular study design, such as randomised controls, were marked as non-applicable and excluded from the scoring calculation. The score for each study was calculated by summing the total scored from relevant items and dividing by the total possible score. Methodological critiques are then presented following the quality assessment criteria by Kmet et al. (2004).

The synthesis part of the review has been organised into two parts: the first covers overall mental health difficulties experienced by deaf children and the second relates to the views of parents and young people themselves in relation to the risk factors and underlying mechanisms identified. The implications of this review for clinical practice and potential future research are then discussed.

Table 5

Summary of the reviewed studies

Number	Study	Country	Aim	Design	Participants	Measures	Outcome	Score (Kmet et al., 2004)
1	The influence of CI on behaviour problems in deaf children. *Jimenez-Romero (2015)*	Spain	**1st aim:** To examine the relationship between auditory integration, communication skills and behaviour problems in a group of deaf children with CI. **2nd aim:** To compare the frequency and intensity of behaviour problems in the group of deaf children compared with the group of hearing children.	Prospective study	2-16 years old 104 deaf participants & 104 hearing participants	ICAP, MAISJ, Ad-hoc Questionnaire	**Finding:** The sample who scored higher in auditory integration and social & communicative skills were the subjects without behaviour problems. Self-injurious behaviours, repetitive and atypical habits, withdrawal or inattention, destruction of objects and disruptive behaviours are significantly higher in deaf children. **Risk factors:** Auditory and social & communication skills	**77%**

2	Mental health of Deaf and Hard of Hearing Adolescents: What the Students say *Brown & Cornes (2014)*	Australia	**1st aim:** To establish the overall incidence of DHH students' self-reports of mental health issues utilising a standardised measure within a group of students varying in terms of degree of hearing loss, family history of hearing loss, means of communication at home and at school, education setting and age. **2nd aim:** To identify the prevalence of the narrowband and broadband syndrome scales in this heterogeneous group. **3rd aim:** To identify which background variables, or combination of variables, was associated with mental health problems	Cross-sectional study	11-18 years old 45 females and 44 males (all deaf)	YSR	**Findings:** 39% of the sample has mental health problems - 40% internalising problems & 37% externalising problems. **Risk factors:** Language used at home - students utilising spoken English with their families emerged as experiencing fewer problems than did those whose families were utilising Auslan or Signed English.	**90%**

3	Peer attachment and social anxiety: gender as a moderator across deaf and hearing adolescents. *Lu, Tian, Yu, Feng & Hong (2015)*	China	To examine the relationship between peer attachment and social anxiety across gender for adolescents who were deaf compared with adolescents with normal hearing.	Cross-sectional study	112 (51 females) deaf adolescents & 133 (65 females) hearing adolescents (age not clear but mean age - 12 for hearing & 15 for deaf)	IPPA & SASC	**Finding:** The relationship between peer attachment and social anxiety varied between boys and girls in the group with normal hearing but not in the group who were deaf. **Risk factor:** Gender is not an issue in deaf group. Special education school is a factor.	**64%**
4	Assessment of behavioural problems in children with hearing loss. *Fiorillo, Rashidi, Westgate, Jacobs, Bush & Studts (2017)*	USA	**1st aim:** This study sought to provide novel information on disruptive behaviour problems in pre-school aged DHH children utilising gold standard behavioural assessment instruments. **2nd aim:** We also examined key family functioning constructs including parenting sense of competence and parenting stress	Cross-sectional study	2-5 years old 39 hearing children, 29 deaf children with HA & 21 deaf children with CI	YC-DISC-IV, PSCS, IFS, PSIF & CDI-III	**Finding:** Hyperactivity, aggression, peer interactions & isolation have been identified in deaf children (48% of HA & 48% CI met ODD criteria compared to 23% in hearing children). **Risk Factors:** Auditory rehabilitation, language impairment, parent-child relationship quality, parenting behaviours & family dynamics	**86%**

5	Can parenting practices predict externalising behaviour problems among children with hearing impairment? *Pino, Castillo, Raya & Herruzo (2017)*	Spain	**1st aim:** To identify differences in the level of externalising behaviour problems among children with and without hearing impairment and in the parenting, styles experienced by both groups. **2nd aim:** To ascertain whether any relationship exists between parenting practices and the level of externalising problems among children with hearing impairment.	Cross-sectional study	6-16 years old 59 deaf and 59 hearing children	BASC, PCRI-M & PBI	**Finding:** Significant differences were found in hyperactivity, behavioural problems and externalising problems but not in aggression. **Risk factors:** Attitudes and parenting practices adopted by mothers and fathers.	**81%**
6	Symptoms of psychopathology in hearing impaired children. *Theunissen et al (2015)*	Holland	**1st aim:** To screen on and compare levels of internalising and externalising symptoms utilising a multidimensional assessment in three groups. **2nd aim:** To examine which risk and protective factors affect levels of psychopathological symptoms.	Cross-sectional study	8-16 years old 57 CI, 75 HA & 129 heating children	CDI, FSSC-R, SCL, CSI, SRIRPA, Delinquency Questionnaire, PSD & own designed social anxiety related questionnaire. Two language tests and CCC-2 were also carried out	**Finding:** HA had significantly higher levels of psychopathological symptoms. **Risk factors:** Type of device was related with internalising symptoms but not with externalising symptoms. Age, language and communication skills predicted psychopathological symptoms	**95%**

7	Aggression Behaviours in Children with and without Hearing impairment. *Babaroglu (2016)*	Turkey	To evaluate deaf children's aggression behaviours and compare the behaviours to hearing children of children with hearing impairment and comparing	Cross-sectional study	81 deaf children and 80 hearing children aged 10 to 17 years old	BPAS	**Finding:** Deaf children demonstrated higher levels of aggression behaviours only if they are aged 14 or over. **Risk factors:** Age and a family member who is also deaf	**46%**
8	Predictors of psychosocial outcomes in hard of hearing preschool children (2016)	Norway	To compare psychosocial functioning in 4-5 years old deaf children with HA	Cross-sectional study	35 deaf children with HA aged between 4 to 5 years old.	SDQ; SSRS; PPVT	**Finding:** More psychosocial difficulties were found in deaf children. Risk factors: Gender and the age of detection	**82%**
9	Behavioural problems in school-aged hearing impaired children: the influence of sociodemographic, lingustic and medical factors (2013)	Germany	To examine several behavioural problems in school-aged hearing impaired children with HA or CI, compared to normally hearing children.	Cross sectional	75 with HA, 57 with CI and 129 normally hearing controls aged between 8 - 16	SRIRPA; DQ; PSD; CSI-4; WISC-III; two comprehension tests; CCC-2	**Finding:** HI children had higher scores for proactive aggression, symptoms of psychopathy, ADHD, ODD and CD when compared to hearing children. **Risk Factors:** Special school, sign language, HA, higher age, male gender, lower SES; lower intelligence and delayed language development.	**86%**

10	Behaviour problems in children with CI (2015)	Taiwan	To examine behaviour problems in Mandarian-speaking children with CI and to investigate the associated factors of problem behaviours.	Cross-sectional study	Sixty deaf children aged between 6 - 18 years old (25 males; 35 females) who used CI for a mean duration of 8 years	CBCL; CAP; SIR; PSI	**Finding:** Significantly more deaf children with CI had higher scores of difficulties across the questionnaires used. **Risk Factors:** Gender, SES and CAP	**86%**
11	Psychological Distress in Bullied Deaf and Hard of Hearing Adolescents (2019)	Taiwan	To determine the prevalence of bullying victimisation among deaf adolescents and ascertain the relation of bullying victimisation experiences and family and school variables with their psychological wellbeings.	Representative study	355 deaf adolescents in 7th to 12th grade. 196 males and 159 females.	SCL and being bullied experience questions	**Finding:** Approximately 65% of deaf adolescents experienced at least one type of bullying victimisation. **Risk Factors:** exclusion bullying, female, delayed bedtime, relationship with parents and peers & dislike for school.	**64%**
12	A study on school adjustment and aggression among adolescents with and without hearing impairments (2019)	India	To examine the level of school adjustment and aggression among the adolescent with and without hearing impairment.	Cross sectional study	60 adolescents aged between 14 to 18 years old. 30 of the adolescents had hearing impairment.	Socio-demographic questionnaire; Aggression scale; Adjustment inventory	**Finding:** No difference in school adjustment among adolescents with and without hearing impairment. Adolescents with hearing impairment were more aggressive. **Risk factor:** Gender	**55%**

13	Screening of psychiatric disorders among hearing impaired children and adolescents aged 4-16 years attending special education institutions in Karachi (2019)	Pakistan	To estimate the prevalence of psychiatric problems and to identify associated factors among hearing impaired children	Cross-sectional study	272 hearing impaired children aged 4-16 years	SDQ; AKUADS & demographic questionnaire	**Finding:** 18% of the children were considered to have mental health difficulties. **Risk factors:** poor class performance, early diagnosis, lack of education (mother) was a protective factor, depression among responding parent	**86%**
14	Psychological difficulties and quality of life in children with hearing impairment and their association with parenting styles (2019)	Turkey	To investigate the relationship between the psychological problems, quality of life and parenting styles in children with hearing impairment	Cross sectional study	84 children (42 HI and 42 hearing controls) aged between 4-10 years old	sociodemographic data form; SDQ; PARI; KINDL	**Finding:** Emotional, behavioural, peer and school related problems were higher in deaf children when compared to hearing controls. **Risk factors:** Overprotective and authoritarian parenting styles	**64%**

	Executive functions, pragmatic skills, and mental health in children with congenital cytomegalovirus (CMV) infection with cochlear implants: A pilot study. Lofjvist et al., (2020)	Sweden	To examine EF and pragmatic skills in relation to mental health in children with aCMV infection	Cross-sectional study	10 children with CMV and 7 children with C26 aged between 4-13 years old	TEA-ch; BRIEF; Serial recall; Sentence completion recall; SDQ; CCC-2; EBA-R; Raven; BNT; Reynell-III	**Finding:** No difference in mental health difficulties between the two groups. Although CMV group reported higher levels of CD and peer problems in CMV group. CMV group had a statistically significant worse pragmatic outcome and phonological working memory than the controls. **Risk factors:** Possibly poor pragmatic outcome and phonological working memory	**73%**
16	Emotions in deaf and hard of hearing and typically hearing children. Tsou et al., (2021)	Taiwan	To investigate emotional functioning and its relation functioning including externalising behaviours	Cross sectional study	55 deaf and 74 hearing children aged between 3-10 years old	EEQ; EmQue; SDQ	**Finding:** Higher levels of empathy related to higher social competence and fewer externalising behaviours. **Risk factors:** Higher levels of negative emotion expression	**77%**

17	The developmental trajectory of empathy and its association with early symptoms of psychopathology in children with and without hearing loss. Tsou et al., (2021)	Belgium	To investigate the development of empathy in children with and without heating loss, and how this development is associated with early symptoms of psychopathology.	Longitudinal study	71 deaf and 272 hearing children aged 1-5 years old at time 1	CDI; EQ; EEQ; ECI-4	**Finding:** Fewer prosocial skills were reported in deaf children and attention to emotions increased with age in the deaf group whereas this remained stable in the control group. **Risk Factors:** Higher levels of affective empathy, lower levels of emotion acknowledgement and larger increase in attention to emotions.	**86%**
18	Behaviour problems in deaf/hard of hearing children: Contributions of parental stress and parenting styles. Chang et al., (2022)	China	To investigate the role of parenting styles in the relations between parental stress and children's internalising and externalising behaviours problems.	Cross-sectional study	74 deaf and 100 hearing children aged between 4-17 years old	PSS; PSDQ; SDQ	**Finding:** Families with deaf children were more likely to engage in permissive parenting and their children exhibited more externalising and internalising behaviours than hearing peers. **Risk factors:** Permissive and authoritarian parenting styles	**82%**

19	Bidirectional dependency of developmental and social difficulties in hearing impaired children on the mother's state of anxiety. Pilarska & Sekula (2019)	Poland	To investigate the influence of mothers' anxiety on their deaf children's development and the influence of the children's developmental level on the anxiety level of their mothers.	Cross sectional study	94 children aged 12-24 months with various levels of hearing loss	STAI; INSITE developmental scale	**Finding:** The mothers' anxiety conditioned the child's poorer development and the child's delayed development had an influence on increasing the anxiety level in mothers. **Risk Factor:** Higher levels of anxiety in mother**s**	**77%**
20	Inattention, Impulsivity, and hyperactivity in deaf children are not due to deficits in inhibitory control but may reflect an adaptive strategy. Gonzalez et al., (2021)	Spain	To determine whether deaf children show higher rates of ADHD and conduct disorder than hearing children. The second aim of the study is to determine whether any behavioural differences between deaf and hearing could be explained by deficits in inhibitory control.	Cross-sectional study	34 deaf and hearing children aged 9-10 years old.	EDHA; Stroop task; ANT	**Finding:** Deaf children showed significantly higher rates of behaviours associated with ADHD and CD**. Risk factors:** Poor receptive vocabulary	**73%**
21	Evaluation of emotional and psycholinguistic problems in deaf and hard of hearing students in the Canary Islands. Rosa & Angulo (2021)	Spain	To evaluate deaf and hard of hearing students' mental health in terms of emotional and behavioural difficulties	Cross sectional study	300 children aged 4-18 years old	SDQ & ITPA	**Finding:** Children with CI exhibited higher difficulties with conduct problems, hyperactivity/inattention and peer problems. **Risk factors:** Hearing devices	**82%**

22	Predicting quality of life and behaviour and emotion from functional auditory and pragmatic language abilities in 9 years old deaf and hard of hearing children. Ching et al., (2021)	Australia	To investigate the influence of functional auditory performance and use of language and speech in real-world environments on children's behaviour and emotion, and on their health-related quality of life.	A cohort study	114 deaf children aged 9 years old	WNV; CELF; CCC-2; PEACH; SIR; SDQ; HRQoL	**Finding:** Behaviour and emotion measurements were in the normal range but with larger SDs. **Risk factors:** Hearing degree, non-verbal IQ, pragmatic language, structural language, auditory function and speech intelligibility.	**95%**
23	The association between deaf identity and emotional distress among adolescents. Lambez et al., (2020)	Israel	To examine the relationship between acculturation patterns and emotional distress among deaf children	Cross-sectional study	69 deaf and 60 hearing adolescents aged between 10-18 years old	BSI; MPSS; DAS; EDS	**Finding:** No significant difference between the two groups in emotional distress, social support and exposure to discrimination**. Risk factors:** Identity acculturation is associated with somatisation score	**82%**
24	The relationships among social-emotional assets and resilience, empathy and behavioural problems in deaf and hard of hearing children. Ashori & Aghaziarati (2022)	Iran	To investigate the relationships among social-emotional assets and resilience, empathy and behavioural problems in deaf children	Cross sectional study	110 deaf and hearing children aged between 3-6 years old	SEARS-Pre; EmQue; SDQ	**Finding:** Empathy, prosocial actions and pro social behaviours had a positive and significant relationship with the social emotional assets and resilience. **Risk factors:** Low level of resilience and social emotional assets are associated with higher levels of behavioural difficulties	**82%**

25	Youth with hearing loss: emotional and behavioural problems and quality of life. Overgaard et al., (2020)	Norway	To compare parent and self-reported emotional and behavioural problems and quality of life among deaf children to norms and to investigate possible associations between emotional and behaviour problems	Cross sectional study	317 children aged 6-18 years old	SDQ and ILC	**Finding:** Deaf children had significantly more parent-reported emotional and behavioural problems**. Risk factors:** Gender, degree of hearing loss	**82%**

(ICAP): Inventory for Client and Agency Planning; (MAIS): Meaningful Auditory Integration Scale; (YSR): Youth Self Report; (IPPA): Inventory of Peer Attchment; (SASC): Social Anxiety Scale for Children; (SDQ): Strengths and Difficulties Questionnaire; (YC-DISC-IV): Young Child Diagnostic Interview Schedule for Children, Version IV; (PSCS): Parenting Sense of Competence Scale; (IFS): Impact on Family Scale; (PSI-SF): Parenting Stress Index-short form; (CDI-III): Communicative Development Inventory III; (BASC): Behavior Assessment System for Children; (PCRI-M): Parent-Child Relationship Inventory; (PBI): Parental Bonding Instrument; (CDI): Child Depression Inventory; (FSSC-R): Fear Survey Schedule for Children-Revised; (CSI-4): Child Symptom Inventories-4; (EAQ): Emotion Awareness Questionnaire; (SCAS): Self-Confidence and Acceptance Scale; (WISC-III): Wechsler Intelligence Scale; (SCL): Somatic Complaint List; (SRIRPA): Self-Report Instrument for Reactive and Proactive Aggression; (PSD): Psychopathy Screening Device; (CCC-2): Children's Communication Checklist version 2; (BYI): Beck Youth Inventory: (CBCL): Child Behaviour Checklist; (ILC): Inventory of Life Quality in Children and Adolescents; (HAWIK): Hamburg-Wechsler Intelligence Scales; (BPAS): Buss -Perry Aggression Scale; (PARI): Parent Attitude Research Instrument; (KINDL): quality of life measurement; (AKUADS): Aga Khan University Anxiety and Depression Scale; (PPVT): Peabody Picture Vocabulary Test; (CELF-4): Clinical Evaluation of Language Fundamentals; (CAP): Categorical Auditory Performance; (SIR): Speech production Intelligibility Rating; (SRIRPA): Self Report Instrument for Reactive and Proactive Aggression; (DQ): Delinquency Questionnaire; (PSD): Psychopathy Screening Device; (SSRS): Social Skills Rating System; (STAI): The State-Trait Anxiety Inventory; (INSITE): Developmental scale; (PSS): Parental Stress scale; (PSDQ): Parenting Styles and Dimensions Questionnaire; (ITPA): Illinois Test of Psycholinguistic Abilities; (SEARS-Pre): Social-Emotional Assets and Resilience Scale for Preschool; (EmQue): Empathy Questionnaire; (BSI): Brief Symptom Inventory; (DAS): The Deaf Acculturation Scale; (EDS): Everyday Discrimination Scale; (MSPSS): Multidimensional Scale of Perceived Social Support; (EEQ): Emotion Expression Questionnaire; (ECI-4): Early Childhood Inventory-4; (WNV): Wechsler Nonverbal Scale of Ability; (PEACH): Parents' Evaluation of Aural/Oral Performance of Children; (SIR): Speech Intelligibility Rating scale; (TEA-Ch): Test of Everyday Attention for Children; (BRIEF): Behaviour Rating Inventory of Executive Function; (EBA-R): Emotional, Behavioural and Attention Rating

Methodological critique

Twenty-five studies examining mental health difficulties in deaf children as well as their risk factors were identified. However, only one study attempted to investigate a possible underlying mechanism (20). Kmet et al. (2004) suggested that papers with a score of over 75% are of good quality; so, scores below 75% were of poor quality. Six papers scored below 75% (3, 11, 12, 14, 15, 20).

Overall, most of the reviewed studies contained an adequate description of their method, participants, and analysis (see Table 5 for more details). These are discussed in greater detail below.

Overview of designs and measures

Fifteen studies were parent-reported; six studies were self-reported (2, 3, 7, 11, 12, 23), and four studies were reported by both deaf children and their parents (6, 9, 21, 25). All studies used questionnaires and only one study conducted a semi-structured interview as well as questionnaires (4). There were large variations in the questionnaires used across the sample of studies reviewed due to differing objectives and the countries in which each study was undertaken, as indicated in Table 5.

Fifteen studies did not explicitly describe their study design. Twenty-two studies were cross-sectional design; one was a prospective cohort design (1); one was a cohort study (22) and one paper was a longitudinal design (17). The latter design gave us an insight into the cause-and-effect relationships between the variables used.

Participants.

All studies were conducted outside the UK, showing a variety of difficulties experienced by deaf children and variables that contributed to those difficulties. The amount of detail given about participants varied across the sample of studies. Seventeen papers did not describe the participants' characteristics adequately, which reduces the generalisability of the results. The details about the characteristics of participants varied across the studies. Only eight studies scored two points (2, 6, 13, 16, 22, 23, 24, 25). None of the papers scored zero points because all of them discussed characteristics to some degree. The papers that scored highest gave detailed information, including participants' mode of communication, age of hearing loss onset (prelingual or perilingual), and whether they know some sign language. They also gave details about the control groups, such as whether the two groups were comparable. Most studies did not describe their participants' ethnicities apart from 4, 5, and 24. These ambiguities make it difficult to extrapolate the results to the general population. Seven papers commented on the parents' characteristics (4, 11, 12, 13, 16, 15, 17), based on their income and/or education levels. Study 13 also shared whether the parents were related, or not as inter-marriage is common in Pakistan and is a well-known risk factor in disability. Only two studies shared the information about preferred mode of communication (9) sign language proficiency (18). However, self-reported on their own skills can be inaccurate due to mismatched communication preference and skills between the parents and the child.

Eight studies recruited participants with a wide age range, and although age was controlled for in most of them, it is likely that developmental influences and differences in relation to age exist in psychological adjustments. Overall, having more detailed information about characteristics would have enabled a better analysis and discussion of the mental health needs and risk factors affecting deaf children.

Seventeen studies scored two points for the method of subject selection and whether they were appropriate. Various sources were used including deaf schools, hospitals, speech and hearing centres, magazines, social centre, and websites. Five studies attempted to recruit participants from more than three settings to reduce any potential selection biases (1, 6, 9, 24, 25). The controls were primarily recruited from schools and day centres. Two studies were not clear about how they recruited hearing controls (10, 14). Twenty-two studies clearly stated that consent for their involvement was obtained from parents, children, and schools, but three of the studies did not say whether they obtained consent directly from families or schools (5, 8, 11). The latter study said that schools gave their consent for the researchers to contact parents but did not say whether parents gave their consent. Four studies recruited from hospitals and the authors of the studies were employed there (4, 14, 15, 19).

Lastly, twenty papers made it clear that the participants recruited were high functioning. They had either an IQ above 80 or a certain level of reading age so that they could access the questionnaires and information to participate in the research. Three studies have stated that deaf children are excluded from the study if they are not able to access questionnaires. Four studies only recruited deaf children who are CI users, oral and attend mainstream schools (16), or those who use total communication (24) or those who wear their CI during all waking hours (15). These narrow criteria are not representative of the heterogenous nature of the deaf population.

Outcome measures.

The instruments used to assess the children's mental well-being were inconsistent across the literature. It is also possible that the different outcome measures used in the studies could have produced different results. The variations may be due to the wording and subscales used. Some differences, therefore, could be related to the different outcome measures used rather than differences between participants.

The most common measure used was Strengths and Difficulties Questionnaire (SDQ) which was used in eight studies. Five studies that used SDQ said the measure had been translated and validated into their language with good levels of validity and reliability. Three studies also translated English questionnaires into their language (15, 18; 19) and three studies discussed the rigorous back-translation process and whether the adapted questionnaires had strong internal consistency (18). However, only two studies translated some measures into sign language (2, 23) and validated for deaf population (23). Some difficulties have raised because of the adaptation process; study (23) reported that an anxiety subscale from Brief Symptom Inventory (BSI) measure was removed after being translated into American Sign Language due to low reliability of BSI anxiety scale in the deaf sample. Another study (2) translated a questionnaire into sign language without the gold standard back-translation procedure, which reduces the reliability and validity of the study. A different approach was taken in study 20 by using a research assistant who is fluent in sign language (20) and in study (21) where teachers repeated some of the items by using different words for deaf students. Unfortunately, these two studies do not ensure that the translation is linguistically and culturally appropriate whilst maintain the reliability and validity of the measures used in the studies.

Eight papers (1, 2, 3, 5, 16, 21, 23, 24) explicitly discussed the reliability and validity of each measure, although these measures are known to have strong reliability and validity which is over 0.7. Although two studies that scored lowly by using the scoring criteria had a construct validity of 0.35 (24) and a newly created questionnaire was used to capture social anxiety in deaf children with no reported reliability and validity (6). This limited the level of generalisability and validity of the results.

O’Rourke and Grewer (2005) suggested that semi-structured interviews were superior to the use of questionnaires for deaf children. Only one study’s authors considered utilising a diagnostic semi-structured interview (4). These interviews used Diagnostic Interview Schedule for Children (DISC-IV), which has proven to be highly reliable with high interrater agreement and criterion validity.

Seventeen researchers were affiliated with either hospitals or universities or both and it is possible that some researchers may have had their own predetermined motivations for setting up such research. They may have adjusted research questions or selected questionnaires that limited other variables being explored.

Analysis

Two studies did not describe the analytic methods employed (7, 12). Consequently, this reduces the internal validity of the study. However, the majority explained their analytic methods very clearly, and all of them were appropriate to their objectives. Most of the papers also included tables and graphs to support their analytical comments, which helped with the readability of the results section. One study also did not include subheadings in the results section (12) and one study did not include graphs for some of results (25). These made the results harder to follow.

Sixteen studies recruited enough participants to detect significant differences between each group. Although, seven studies had a small sample size (4, 8, 15, 16, 17, 20, 24) or different sample size between groups (17, 18). As a result, this led to reduced statistical power and/or issues with confounding variables. Thus, overall, for these studies, a small effect size was not detected between groups. This could have been due to the availability of participants, lack of parental consent, or some deaf children being unable to complete tasks required of them due to poor understanding of what was required of them.

This suggests that other variables which did not reach a level of significance may have contributed to the mental health needs of deaf children.

Twenty-one papers attempted to control for confounding variables. Only three papers did not clarify whether confounding variables were controlled for (1, 14, 22). A paper stated that some of the confounding variables were not controlled for (24). It may therefore be that some dependent and independent variables were influenced by these confounding variables, distorting the results.

Synthesis finding

In line with the aim of this review, all studies sourced were based on mental health and/or wellbeing in general, along with contributing factors. Studies were organised into themes. The next section gives a synthesis of those key themes.

Behavioural and emotional difficulties experienced by deaf children

All but eight papers (3, 11, 13, 15, 19, 21, 23, 24) presented evidence of higher levels of emotional or behavioural difficulties in deaf children when compared to hearing or normative samples. Three studies that did not report higher levels of mental health difficulties in deaf children had a percentage score of below 75 according to Kmet et al's appraisal checklist, thus these papers should be interpreted with caution (3, 11, 15). Two papers did not report whether deaf children had higher levels of psychological difficulties (11, 24) as they had a slightly different focus on the psychological distress experienced by deaf children. The former study demonstrated that at least 65% of deaf children have been bullied compared to approximately 25% hearing children and this contributes to higher levels of mental health difficulties in that group. In relation to relationships, lower levels of resilience and social-emotional skills contributed to higher levels of behaviour difficulties in deaf children (24).

Overall, the prevalence of mental health difficulties in deaf children ranged from 18% to 80%, which suggests large variations across the papers. Eighteen papers reported higher levels of behavioural difficulties in deaf children compared to emotional difficulties, which are 18% to 80% and 9.6% to 65% respectively. Only one study reported that deaf children experience two or more mental health difficulties in their lifetime (11). A summary of the types of mental health difficulties is demonstrated in Table 6.

Table 6

Types of mental health difficulties

The most common reported difficulties	The least reported difficulties
Hyperactivity/inattention	Atypicality
Externalising	Emotional
Peer difficulties	Thought difficulties
ODD	Somatisation
Behavioural difficulties	Depression
	Withdrawal

A wide range of difficulties were explored, which made direct comparisons difficult. The most common reported difficulties are externalising difficulties, although they are defined differently due to different outcome measures used. Different outcome measures, the heterogeneity of participants and different aims of each paper make direct comparisons difficult. Three papers reported more ambiguous behavioural definitions, and this was due to measurements used; these were behavioural problems (5, 14) and externalising problems (5). Twenty studies that addressed the mental health needs of deaf children attempted to identify those needs by comparing the deaf group either between CI and HA or with hearing counterparts either with a 'control' group or normative sample. However, in two studies, the normative samples were from different countries (21) or different age (25)

Respondents.

All studies identified various mental health difficulties in deaf children, as reported by deaf children themselves, their parents or both. Parents are usually asked to report on their deaf child's difficulties if the child is really young i.e., one to six years old (8, 17, 19, 24), aged nine to ten (20, 22) or the range age is really large i.e. four to 18 years old (15, 16, 18, 21). Where deaf children are asked to report on their difficulties, they are usually between 10 to 18 years old (23), which is considerably older and has narrower age range when compared to parent-reported papers. Three papers (6, 9, 25) used both parents' and deaf children's reporting– the age range is similar to the parent-reported papers i.e., six to 16 years old. These deaf children can self-reported only if they are over a certain age.

When deaf children are asked to report on their difficulties, the authors' focus would be on psychological difficulties, such as aggression (7, 12), social anxiety (3), identity (23) and bullying experience (11). Only two papers explored self-reported general difficulties; the aim of this paper was to explore subjects' overall experience (2). The remaining papers, where reports were by parents or both, focussed on general difficulties experienced by deaf children, with three papers exploring only behavioural/externalising difficulties (4, 5, 9). Some risk factors are related to parenting styles (5, 14, 18), empathy (17, 24) or rehabilitation-related variables (1, 10).

A general finding across all studies was that the younger a child is, the more likely parents will be asked to report on their difficulties. The difficulties investigated then tend to be more generic compared to self-reported difficulties. Finally, all papers have their own idiosyncratic themes or factors depending on the overarching aim of the study.

Parents: Risk factors related to mental health difficulties in deaf children.

Rehabilitation factors

Rehabilitation-related factors were the most common main theme when parents were involved in the research. Several studies explored variables related to rehabilitation, such as age of detection, age of implantation, hearing device, understanding speech, and having good speech and/or listening skills. These factors were measured in different ways, including demographic questionnaires, which made direct comparisons difficult.

Age of detection.

Four studies (6, 8, 13, 17) found a significant association between age of detection and mental health difficulties experienced by deaf children. Two studies (6, 8) indicated that early detection significantly contributes to better psychological outcomes. In contrast, the other study demonstrated that later detection is a protective factor (13), with study 17 specifically stating that detection after 6 months of age has a protective effect on deaf children's mental health difficulties. A critical difference between these studies was the continents they were conducted. In the first two studies were carried out in Europe whereas the other two were carried out in Asia (Israel and Pakistan). Different cultural beliefs, attitudes and values may have had an impact.

Hearing devices.

Six papers explored associations between hearing devices and difficulties experienced by deaf children (1, 4, 6, 9, 10, 21) and they found that hearing devices had a significant impact on the difficulties experienced by deaf children. Four papers compared CI and HA users as a subgroup; CI users had significantly fewer psychological difficulties compared to HA users (4, 6, 9), apart from one study demonstrating that CI users exhibited significantly higher levels of conduct problems, hyperactivity/inattention and peer relationship difficulties compared to HA users (21).

However, CI users are not without difficulties; all papers demonstrated that CI users exhibited significantly more psychological difficulties compared to hearing samples.

Implantation.

A significant association was found between duration of CI (9) and psychological difficulties in CI users. It was generally found that the earlier the child is implanted, the less likely the child will experience difficulties in their lifetime. As with other findings there are big variations in the CI sample, with some CI users struggling with their psychological wellbeing even though they had been wearing CI for at least eight years (10). It was also difficult to assess the impact of the implantation duration, especially when studies had a wide age range and the inclusion criteria were different for each study, ranging from 6 months (9) to 8 years (10) since the implantations.

Speech.

Generally, deaf children with higher levels of speech are less likely to experience mental health difficulties in their lifetime (10). These deaf people with good speech skills are more likely to have better prosocial skills compared to other deaf children with lower score of speech intelligibility. However, it was difficult to compare directly across the papers because of the different parent-reported or self-reported measures (21) used to assess mental health difficulties in deaf children and different professionals measuring speech skills in deaf children (10 15, 21).

Language and communication skills.

Four papers found that deaf children with better language and communication skills are more likely to have significantly better mental wellbeing (4, 6, 22, 25). The explained variance for communication skills and externalising symptoms was as high as 54% (6). As with other findings, there is a large variation in the deaf sample and a large subgroup within the deaf sample exhibited lower language and communication skills compared to hearing peers. These findings are partly supported by study 4 where Deaf children scored between 2.5% to 20% in language tests compared to 50% for hearing children (4). Interestingly, it was the CI group that scored 2.5% in the language tests, with HA users scoring 20%. All deaf children were without developmental delay, which suggests that language difficulties may arise due to environmental factors; these have not yet been explored extensively.

Relationships difficulties

This section focuses on relationship difficulties exploring family context, parenting style, and peer difficulties. Five papers focused on relationship difficulties which are reported by parents.

Family context.

Three of the papers explored the importance the family context and how it may impact on mental health difficulties (10, 13, 19) and two papers demonstrated significantly higher mental health difficulties in deaf children (10, 19). One paper found that depression among responding parents was identified as a risk factor (13), while the other two provided a useful insight of why this may be. The stress (10) and anxiety (19) levels were significantly higher in families with a deaf child, and this contributed to significantly higher levels of difficulties experienced by deaf children. The latter study (19) demonstrated that delayed developments in deaf children contributed to significantly higher levels of anxiety in mothers and this relationship is bidirectional.

One study (13) found that the incidence of mental health difficulties in deaf children was only 18% in Pakistan, which was comparable to the hearing population. It reported that all parents signed fluently in this study. It may be the case here that the quality of communication at home, rather than the mode of communication, is the protective factor. In two other papers reviewed (10, 19), parents reported that their deaf child used oralism and that it is the communication challenges that contribute to higher levels of stress in parents. None of the papers explored the quality of the communication e.g., the length of interactions, appropriate use of words and the kind of questions asked (i.e. closed or open questions).

Parenting styles.

Three papers looked at parenting styles and how they are associated with psychological difficulties in deaf children. It was found that permissive (18), overprotection (5, 14) and authoritarian (14, 18) parenting styles were associated with significantly more externalising and emotional difficulties in deaf children. Additionally, these parental attitudes were recorded significantly more in the deaf group compared to hearing group (14); however these results should be interpreted with caution because study (14) scored below 75%.

Peer Difficulties.

Five papers explored social difficulties in deaf children and found that they were significant (10, 16, 17, 18, 24). Study 10 showed that deaf children from lower SES households were significantly more likely to demonstrate social difficulties compared to hearing peers. However, one study found that deaf children did not have prosocial difficulties, but rather peer difficulties (18). Three studies explored the levels of empathy in deaf children and the effect of this on their wellbeing (16, 17, 24). All three demonstrated that deaf children were more likely to exhibit peer and/ prosocial difficulties because of how they process empathy compared to their hearing counterparts. These studies suggested that deaf children lack skills in managing their emotions, such as regulating skills and coping strategies to manage their arousal. Study 15 provided an insight of why this may be the case, by comparing deaf children with Cytomegalovirus (CMV; a type of syndromic deaf gene) and another with a different, non-syndromic deaf gene , although this may not tell the whole story due to the paper scoring below 75% using the Kmet criteria. It was found that deaf children with CMV were more likely to have peer problems. These children have reduced executive function (EF) skills, a set of skills such as planning, inhibitory control, and an ability to follow instructions (Faraone & Radonjić, 2023). This implies that there are cognitive variables that may have an impact on their cognitive function, which in turn affects their peer and prosocial skills development.

Cognitive factor

Inhibitory control

Only one study attempted to explore an underlying mechanism, which is the effect of inhibitory control, one of the core EF skills, on deaf children's attention deficit hyperactivity disorder (ADHD) related behaviours (20). The study found that the inhibitory control scores did not differ between deaf and hearing, even though over 85% of the deaf children compared with 14% of hearing children in the study presented with ADHD symptoms. The authors concluded that it may be an adaptive strategy in deaf children to access information from their environment which is not available to them via audition. This needs to be investigated and understood further.

Demographic variables

Socioeconomic (SES) status.

Four papers reported an association between SES and mental health difficulties in deaf children (9, 10, 11, 13). They are at higher risk of developing aggression (10), social difficulties (10), ADHD (9) and psychopathy symptoms. Deaf children from lower SES backgrounds were more likely attend special schools and use sign language (9, 11).

SES is measured by several variables, including education (Psaki et al., 2014). One paper found that a mother's lack of education had a protective effect on psychiatric problems whereas a father's lack of education increases the risk (13). This may reflect a paternalistic culture where men work to provide for their family whilst women stay at home to manage the household.

Gender.

Four studies revealed an association between gender and mental health difficulties in deaf children. Males are significantly more likely to demonstrate higher levels of overt behaviours, such as aggression (10, 12), delinquency (9) behavioural (25) and ADHD (9) compared to females. This trend is in aligned with the hearing population.

Age.

Age also played a role in this study. It was found that the older participants were more likely to demonstrate significantly higher levels of delinquency (9) when compared with a hearing sample. It was also found that from the age of 14 onwards aggressive behaviours observed in deaf children reached a level of significance compared to their hearing peers. Larger increases in attention to emotions were noted in older deaf children when compared to hearing children and this contributed to significantly higher levels of difficulties in deaf children (17). The pathways to the higher levels of difficulties in deaf children as they age were unexplored.

Young people: Risk factors related to mental health difficulties in deaf children.

The risk factors are grouped using main themes, as in the parents' section above. Rehabilitation factors featured less than when parents were involved (three papers compared to twelve). This means different variables were explored, particularly relationship difficulties.

Rehabilitation factors

Rehabilitation.

Only three papers explored rehabilitation-related risk factors (9, 12, 21). Consistent with other findings, deaf children were significantly more likely to be more aggressive (12) and to exhibit delinquency behaviours (9) when compared to hearing peers. However, it was not clear whether deafness itself is a risk factor (12).

In line with other findings, CI users demonstrated lower levels of aggression compared to HA users (9). This is, however, dependent on the duration of CI at the time of the test; the longer the child had been wearing CI, the less likely they were to experience difficulties. Study 21 demonstrated that CI users were more likely to exhibit conduct, hyperactivity and peer difficulties when compared to HA users. The authors concluded this was because the HA users received more support at school compared to CI users due to higher learning needs.

Relationship difficulties

Being understood.

Two papers reported on the effect of language mode on mental health difficulties (2, 9). It was found that deaf children who used oralism with their families tended to experience significantly fewer emotional and behavioural difficulties compared to those who communicated using sign language. This suggests that there are some difficulties experienced by deaf children who use sign language at home, such as being misunderstood and mismatched fluency levels. However, these variables remain unexplored. Also, to note is that teachers decided whether a child’s sign language was good enough for them to be included in the study (2) which implies high level of fluency in these children, reducing the generalisability of the study.

Conflicts.

Deaf children generally have weaker peer attachment; thus, they have significantly fewer friends (3) significantly increased prosocial difficulties (25) and are significantly more likely to be bullied and victimised (11) compared to hearing peers. Additionally, they are more likely to experience discrimination and lack of social support (23) which contributes to higher levels of emotional distress; however, the internal validity of this study (23), and its significance, was reduced because the anxiety subscale was removed from BSI questionnaire. Studies 11 and 23 provided some exploration of risk factors, which included conflicts with parents, peers, dislike of school and identity acculturation (23). Two studies (3, 11) scored below 75%, therefore these results should be interpreted with caution. As with other studies, underlying mechanisms were not explored.

Being treated differently.

Sixty four percent of deaf children attended pre-school as compared to 35% of their hearing peers (7). Hearing children are more likely to be with their parents to work in agricultural fields and this is the reason for the lower rate of pre-school in the hearing group which suggests that deaf children are treated differently by their parents. These deaf children showed significantly higher levels of aggressive behaviours compared to their hearing peers. Underlying mechanism variables to those aggressive behaviours were not explored.

Sociodemographic variables

Gender.

It was found that deaf boys are significantly more likely to be aggressive than deaf girls (7, 12) which is consistent with findings in the hearing population. Interestingly, it was found that hearing girls tend to experience significantly higher social anxiety when compared to deaf girls (3). The difference in relation to social anxiety between deaf girls and deaf boys were comparable, which is not aligned with the trend in the hearing population. The deaf sample in this study is significantly younger than the hearing sample, which may explain the insignificant results and this is partly the reason why the paper scored below 75% (3).

Discussion

The primary findings are that deaf children are more likely to exhibit higher levels of emotional and behavioural difficulties compared to their hearing peers. This is consistent with the 2013 review, and, as in that review, the actual prevalence of mental health difficulties in deaf children is not clear due to inconsistent use of measures, participants and lack of underlying mechanisms being investigated. More behavioural difficulties are reported and found to be significant when compared to reported emotional difficulties. This may be because behavioural difficulties are more visible, making them easier for parents to report accurately compared to emotional difficulties.

Parents' perspective

When parents are involved in studies, researchers seem to use questionnaires and variables that are more focused on rehabilitation factors, such as type of device, speech and listening skills. That limits the parents' perspective on the possible risk factors related to their deaf child’s mental health difficulties. As a result, the positioning of these studies is far more likely to become medicalised, which means a variety of relational and social variables remain largely unexplored.

According to the papers reviewed, parents are more likely to be anxious (19), stressed (10) and demonstrate permissive (18), overprotective (5, 14) and/or authoritarian (14, 18) parenting styles and these factors increase the risk of deaf children developing mental health difficulties. Additionally, parents in the papers reviewed (5, 10, 14, 18 and 19) are more likely to record that their deaf child is experiencing peer difficulties. As underlying variables remain unexplored, based on the current literature, it is possible that deaf children are experiencing peers difficulties because of language (Hall et al., 2023), social (Cawthon et al., 2018) and cognitive barriers (Continisio et al., 2023).

It is worth noting that CI users enjoy higher levels of support from an early age compared to HA users due to higher levels of needs (Muller et al., 2023). The higher support may have provided some levels of containment for families with a deaf child (Continisio et al., 2023) and this is partly supported by a paper reviewed (19). Twelve studies, however, show that CI users, who demonstrate good levels of speech and listening skills, still exhibit higher levels of mental health difficulties than their hearing peers, with a large variation in the group. This suggests that some unexplored factors may have a greater effect than increased access to sounds; a parent’s positive attitude may contribute to better outcomes in deaf children, for example (Jackson et al., 2008; Szarkowski & Brice, 2020) and the positive attitude can be enhanced by having more professional involvement (Szarkowski & Brice, 2019).

It is difficult to obtain accurate statistics on the percentage of hearing parents who sign with their deaf child as these are not generally recorded. The most recent report that was carried out in 2013-2014 indicated that 22.9% of deaf children use sign language at home on a regular basis (Office of Research Support and International Affairs, 2014). This lack of fluent communication represents a loss of opportunity for a deaf child to develop a theory of mind, emotional regulation, coping mechanisms (Sreedhar & Srikanth 2016) and social rules (Batten, Oakes & Alexander, 2014). It is clear that language fluency and/or the number and quality of parent-child interactions need to be explored in the future studies.

Parents in lower SES are more likely to have a deaf child with mental health difficulties. It is well documented that families from lower SES have less social support and resources and are living with higher levels of stress due to financial, employment and health difficulties (Scrimin et al., 2022), which means they may have less resources to communicate with their deaf child, especially if they must pay to access sign language courses (NDCS, 2022).

Deaf children's perspective.

As with a parent's perspective, when the focus is on deaf children, it is researchers who determine which measures to use. This limits deaf children's ability to express the difficulties they experience. Researchers seem to think that the deaf children are more likely to suggest that their relationships with families and peers are potential causes of their mental health difficulties.

However, many of the studies demonstrated that deaf children have peer and prosocial difficulties and are more likely to have conflicts, as discussed by the young people involved in this review. These deaf young people have reported that they are more likely to have fewer friends (3), experience being bullied (11) and discrimination, and have less social support (23). The authors suggested that these deaf children lack regulation and coping skills to manage their emotions which is reflective of a recent review on deaf children (Freitas et al., 2022). These may contribute to the difficulties faced by deaf children and their mental health difficulties.

Underlying mechanisms

One study attempted to explore an underlying mechanism in deaf children and their ADHD symptoms. Interestingly, it was found that deaf children's inhibitory control skills are similar to their hearing peers, even though 85% of deaf children presented with ADHD symptoms compared with only 14% hearing children. The authors concluded that it may be an adaptive sensory strategy for deaf children to access their social world. This implies that there are false positive results that may be occurring when deaf children are being screened for ADHD or behavioural difficulties. This study scored below 75% using the Kmet checklist, therefore it should be interpreted with caution.

Limitations.

Most studies used cross-sectional design, which means cause and effect cannot be examined. This means that results should be interpreted with caution, especially where researchers predetermined the variables. It is possible that many useful variables have remained unexplored in the literature, and it may be beneficial to introduce different designs, such as longitudinal or qualitative designs, to this area of research. The sample size in some studies was also too small, which meant that some risk factors were deemed to be insignificant.

All studies used different measurements to assess the difficulties experienced by deaf children. They attempted to use standardised measures that are valid and reliable.

However, most measures have not been validated for the deaf population and with underlying mechanism variables largely unexplored, this can create false positive results; an example would be a child’s behavioural problems being more likely to be recorded because of the parent’s perception of deafness and belief that their deafness affects the dynamics within a hearing family (Studts et al., 2022). This supports Blennerhasset’s (2000) statement that assessments appropriate for the deaf population are lacking in quality and quantity. As a result, a lot of deaf children were excluded because they were not able to access the measures adequately. O’Rourke and Grewer (2005) suggested that semi-structured interviews are better than questionnaires for deaf children.

None of the studies used qualitative methods, which may mean that parents’ and/or children’s experiences are being missed. Additionally, Griggs (2000) notably suggests that the most appropriate comparison group for deaf people is not the hearing population but other deaf people. Equally, it would be beneficial to compare deaf parents with deaf children and hearing parents with deaf children. Either of these alternative approaches could reveal some unexplored variables.

Lastly, whilst researchers identified multiple and useful risk factors, they do not explain the pathway to the outcome. Rutter (2000) said “a variable is hardly a mechanism”; several studies have found that deaf children are more likely to have theory of mind delay (Schick et al., 2007). None of the papers in this review explored theory of mind delay due to language deprivation as a possible mechanism.

Clinical implications

Most of the findings support previous assertions that deaf children have higher levels of mental health difficulties compared to their hearing peers. More specifically, deaf children are more likely to demonstrate behavioural and emotional difficulties. These findings have important implications for clinical practice.

Clinicians have a role in supporting deaf children and their families. They can learn how their mental health difficulties manifest and their possible causes. The findings suggest that parents may have adopted a medical and auditory perspective in relation to their deaf children's difficulties. Clinicians could play a positive role in changing this perspective by working with families and professionals to explore different ideas of deafness. This will change the family dynamics. Psychoeducation could also be provided to counter the impact of deaf children being in a hearing environment. As deaf children have social/peer difficulties, clinicians could work with them to explore coping strategies and developing their social skills.

The finding in relation to ADHD symptoms and inhibitory control demonstrates that some measures may not be suitable for deaf children. Clinicians, especially those in mainstream CAMHS services, need to be mindful of which measures to use to screen symptoms in deaf children. In line with O'Rourke and Grewer's (2005) suggestion, interviews by clinicians with expertise should be carried out with families when exploring symptoms in deaf children to minimise the risk of false positive results. In order to build expertise, clinicians should be updated with the latest evidence-based research in order to inform their practice with deaf children and families.

Research implications

Future research must adopt a more longitudinal design to explore causal factors. In order to move away from diagnostically driven element of the measures used and to garner further understanding of the different factors affecting deaf children's psychological wellbeing, qualitative methods need to be used, conducted with either parents, deaf children themselves or in combination.

Some sample sizes were insufficient, which meant some vital variables did not reach significance, preventing the detection of further differences between subgroups. More investigations with larger sample sizes are needed, especially when comparing subgroups. Deaf children of deaf parents should be included in the research as there are some findings that deaf children of deaf parents do as well as hearing peers. Additionally, the exclusion of deaf children with language or cognitive difficulties needs to be reduced to ensure the results are more representative of the deaf population.

There are large variations in the deaf sample, with some functioning very well and others not. But to explore individual differences, there must be more research into underlying mechanisms, such as theory of mind. It may also be useful to include deaf researchers to provide a more cultural-linguistic model and to assist in adapting the measures for the deaf population. This will shape how research questions are formulated and make sure tools used are linguistically accessible to deaf young people.

Conclusion

This review explores the mental health needs of deaf children and associated risk factors. The papers reviewed identified a variety of factors that affect the mental well-being of deaf children. The papers were split into the two domains of parents and deaf children; the papers using parents' perspectives were more medicalised and had a more rehabilitation-related focus than those that used children's reports. In contrast, relationship difficulties were explored in depth when young adolescents were involved. Some useful risk factors, such as relationship difficulties and parenting styles, were identified, but the pathways to the risk factors remain unexplored. Future research should include different designs to explore missing psychological variables and mechanisms that contribute to the mental health difficulties of deaf children.

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Appendix A: Kmet (2004) Quality Assessment Criteria

- Question/objective sufficiently described?
- Study design evident and appropriate?

- Method of subject/comparison group selection or source of information/input variables described and appropriate?
- Subject (and comparison group, if applicable) characteristics sufficiently described?

- If interventional and random allocation was possible, was it described?

- If interventional and blinding of investigators was possible, was it reported?

- If interventional and blinding of subjects were possible, was it reported?
- Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?
- Sample size appropriate?

- Analytic methods described/justified and appropriate?
- Some estimate of variance is reported for the main results?
- Controlled for confounding?
- Results reported in sufficient detail?
- Conclusions supported by results?

Appendix B

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**21**	**22**	**23**	**24**	**25**
Question/objective sufficiently described?	2	2	1	2	2	1	1	2	2	2	1	2	1	2	2	1	2	2	2	1	2	2	2	2	2
Study design evident and appropriate?	2	1	1	1	0	2	1	1	2	2	1	1	2	1	1	2	2	2	1	1	1	2	1	2	1
Method of subject/comparison group selection or source of information/input variables described and appropriate?	2	2	1	2	2	2	1	2	2	1	2	1	2	1	1	1	2	2	2	2	1	2	2	2	2

Subject (and comparison group, if applicable) characteristics sufficiently described?	1	2	1	1	1	2	1	1	1	1	1	1	2	1	1	1	2	1	1	1	2	2	2	2	1
If interventional and random allocation was possible, was it described?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
If interventional and blinding of investigators was possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
If interventional and blinding of subjects were possible, was it reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?	1	1	1	2	1	2	1	2	2	1	1	1	2	1	2	1	1	2	1	2	2	1	1	1	2
Sample size appropriate?	2	2	2	1	2	2	2	1	2	2	2	1	2	2	1	1	1	1	2	1	2	2	1	1	2
Analytic methods described/justified and appropriate?	2	2	1	2	2	2	0	2	2	2	2	0	0	2	2	2	2	2	2	2	2	2	2	2	2
Some estimate of variance is reported for the main results?	2	2	2	2	2	2	2	2	2	2	1	1	2	1	2	2	2	2	2	2	2	2	2	2	2
Controlled for confounding?	0	2	2	2	2	2	1	1	2	2	1	0	2	1	0	2	1	1	1	1	1	2	1	0	0

Results reported in sufficient detail?	2	2	1	2	2	2	1	2	2	2	2	1	2	0	2	2	2	1	2	2	2	2	2	2	2
Conclusions supported by the results?	1	2	1	2	2	2	2	2	2	2	2	1	2	1	2	2	2	2	1	1	1	2	2	2	2
Total	**17**	**20**	**14**	**19**	**18**	**21**	**13**	**18**	**19**	**19**	**14**	**10**	**19**	**13**	**16**	**17**	**19**	**18**	**17**	**16**	**18**	**21**	**18**	**18**	**18**

JOSIE MULLOY BSc (Hons.) MSc

MAJOR RESEARCH PROJECT

SECTION B

What are hearing parents' experience of having a deaf child with mental health difficulties: Interpretative Phenomenological Analysis

WORD COUNT: 7988 (577)

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor in Clinical Psychology

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Abstract

Background: The existing literature consistently highlights that a higher proportion of deaf children are more likely to experience mental health difficulties when compared to hearing children (65% to 15% respectively). Most of these are from hearing families and the research to date has focused on whether cochlear implants are successful in reducing mental health difficulties in deaf children. Other variables, such as familial stresses and family dynamics, remain largely unknown. The current study has therefore sought to explore how hearing parents have made sense of their deaf child's mental health difficulties.

Methods: Semi-structured interviews were held with seven hearing parents who have a deaf child in National Deaf Children and Adolescents Mental Health Services (NDCAMHS). Data were analysed using Interpretative Phenomenological Analysis (IPA).

Results: The research suggests that the parents are on a lifetime journey of sense-making in the context of high levels of uncertainties and stresses. This results in them experiencing a range of emotions and identities whilst navigating an unknown world with their deaf child who has mental health difficulties. Three superordinate themes emerging from the data were: deafness as a voyage, living with uncertainty and parenting on another level.

Conclusions: Findings highlighted that hearing parents face daily challenges in the context of high uncertainties. These are emotionally difficult and painful for these parents. They suggest that parents would benefit from some interventions in relation to sense-making, developing strategies and increasing their tolerance of uncertainties. Research implications are discussed.

Keywords: deaf children; mental health difficulties; hearing parents; qualitative research

Introduction

Over ninety percent of deaf children are born to hearing parents (Mitchell & Karchmer, 2004). Most of these parents have no prior experience of deafness (Marshark et al., 2018). These parents may be overwhelmed with acquiring new knowledge, learning how to interact and communicate with their deaf child and navigating the personal and familial process of adjustment for the family (Young 2010; Young & Russell, 2016) whilst grieving for the child they never had.

In response to the diagnosis, these parents may grieve for the 'perfect' child they never had (Kurtzer-White & Luterman, 2003). As their child is still physically present, the parents' grief can be described as ambiguous loss (Boss & Yeats, 2014). The authors found that ambiguous loss creates complicated grief in these parents because there is no possibility of resolution in the context of ambiguity. With ambiguous loss, grief is often disenfranchised by professionals and the systems due to their impatience with ambiguity. It is defined as 'grief that people experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported' (Boss & Yeat, 2014; p68).

Gregory's (1993) study discussed the grief that hearing family of a deaf child goes through is based on a medical model of deafness, which is also supported by a more recent paper by Young (2003). A medical model is applied when parents or/and professionals choose to focus on the absence of hearing, thus, viewing deafness as disability (Reagan, 2020). With the medical model of deafness in mind, the adjustment process that hearing parents of a deaf child go through may be solely managing something that is 'damaged', to be recovered from it as quickly as possible (Lane, 1992). This is partly supported by more recent papers where 84% of parents decided to implant their deaf child because they want their deaf child to hear and speak (Hemer & Chur-Hansen, 2021). This is aligned with the current system where the first people parents meet in the diagnosis process are audiologists and doctors. The model often presented by these professionals is the medical model of deafness. The medical model influences the parents to ‘fix’ their deaf child by opting for either hearing aids or cochlear implants and by teaching them how to speak. For many parents, their main objective is to integrate their deaf child into the hearing world, which is essentially is part of their’ world (Mauldin, 2012; Harris, Hemer & Chur-Hansen, 2021). This is supported by Young’s (1999) study where it was found that the models of understanding deafness have an impact on parental decision-making. The parents who have adopted the medical perspective are more likely to implant their deaf child and encourage them to listen and speak. In contrast, these with more cultural perspective are more likely to use sign language with their deaf child.

The medical model of deafness stands in contrast to the social model of disability and cultural model of deafness. The latter is preferred by the deaf community, especially by deaf people who do not label themselves as disabled (Putnam et al., 2022). These deaf people tend to use sign language to communicate with each other and would generally advocate hearing parents to sign with their deaf child; they will often reject the notion of having their deaf child implanted (Putnam et al., 2022). There is a strong evidence base that sign language can boost deaf children’s speech and English skills (Hoffmeister et al., 2022), but this information is often ‘withheld’ from hearing parents by professionals (Hall et al., 2019). The social model suggests that the problem is not within deaf individuals, but within a society that is not designed for them, i.e., by not providing accessible information and by most people not knowing sign language.

Mental health in deaf children

The research has demonstrated that up to 65% of deaf children will experience mental health difficulties compared to 15% of hearing children (Brown & Cornes, 2015).

There is some evidence that delayed language acquisition, in other words, language deprivation, in either modality (speech or sign language), increases the risk of mental health problems developing in deaf children (Hall, 2017). Such delays do occur in many deaf children, especially from hearing families (Hall, 2017; Hall et al., 2019). The current literature related to language deprivation has shown that the delay in deaf children can cause cognitive delays, such as theory of mind, executive function, and memory (Glickman, 2018). Additionally, interpersonal trauma is more likely to be experienced by deaf children, a unique experience of being a deaf child in a hearing world (Anderson & Leigh, 2011; Anderson et al., 2016). As hearing parents often do not know how to raise a deaf child, they will generally rely on the expertise of teachers or other professionals. The problem, however, is that language development for deaf children is not covered in their professional education (Hall, 2017); this increases the likelihood of flawed advice being given to hearing parents on how to raise their deaf child. This flawed advice will also influence the parents' decision-making processes (Young, 1999).

Several studies demonstrated that deaf children of deaf parents outperform deaf children from hearing families in language, academic functioning, and psychosocial adjustment (Johnson, 2021). Musselman's (2000) study demonstrated that these deaf children thrive because of a fully and naturally accessible language environment. Deaf parents also demonstrated a high level of knowledge, acceptance, and preparedness to raise a deaf child, including how to interact with their deaf child to maximise information inputs (Beatrijs et al., 2019).

Parents' experience of children with mental health difficulties

It was not until recently that the experiences of parents of children with mental health difficulties have been explored. The current literature has demonstrated that a higher number of losses are experienced by parents when their child develops mental health difficulties. It is hypothesised that parents of children with mental health difficulties may be experiencing ambiguity loss and disenfranchised grief (Macgregor, 1994). Thus, in the context of hearing parents with a deaf child, the parents' experience of grief and ambiguity loss could be retriggered. The author elaborated that some risk factors that increased the likelihood of grief experienced are related to other people's failure to recognise their experience of loss. It has been found that stress levels in these parents are higher compared to parents of children without mental health difficulties (Reiss et al.,2019). Brown's (2018) study also demonstrated that parents of children with mental health difficulties experience feelings of uncertainty, helplessness, and frustration.

Rationale for the research

To date, previous research has mainly focused on measures and variables the researchers were interested in studying. This means the lived experience of the parents has not been captured. In summary, there is no research to date that explores hearing parents' experience of having a deaf child with mental health difficulties. This study was felt to be important in addressing a unique gap and to extend the current literature. It is also critical to understand these parents' lived experience as well as highlighting what support may be needed for them.

Aims of the research

To gain an in-depth understanding of hearing parents' experience of having a deaf child who is experiencing mental health difficulties, as seen in Table 1:

Table 1.

Research questions

1	What are hearing parents' experiences of having a deaf child who is experiencing mental health difficulties?
2	How do hearing parents make sense of their deaf child who is experiencing mental health difficulties?

Methods

Design

Flexible, semi-structured interviews were used to engage with participants in the study, with Interpretative Phenomenological Analysis (IPA; Smith et al., 2009) being used to analyse the interviews. In IPA, the researcher makes sense of the participants' lived experience through a process of careful interpretation, which is described as a double hermeneutic approach (Reid et al., 2015). IPA has often been used to capture parents' experience of having a disabled child (Eskandari et al., 2022; Rabbitte et al., 2017) and aims to understand how people make sense of their experiences (Smith et al., 2009). IPA was thus felt to be the appropriate method of analysis, especially in an area that is currently under researched.

Participants

Smith et al. (2009) recommended a sample size up to ten participants for IPA studies due to the focus on understanding a phenomenon within a specific context. Therefore, a purposive sampling strategy was used to recruit participants accessing a National Deaf CAMHS under two different NHS trusts. Eight participants were recruited, which is within the suggested sample size for IPA (Smith & Osborn, 2004); however, one participant withdrew after their interview. This meant that seven participants completed their interview and consented to their data being used. To ensure that the sample was as homogenous as possible, Table 2 outlines the inclusion criteria:

Table 2.

Inclusion criteria

1	The parent was hearing
2	The parent had a deaf child aged up to 18 years old.
3	The deaf child had been diagnosed with emotional or/and behavioural difficulties.
4	The parent was an English speaker.

National Deaf CAMHS accept deaf children from birth to eighteen years old and due to the small number of families within the service, there is no age restriction in place in terms of criteria to support recruitment. All participants apart from one were mothers aged between 30 – 52 years. They each had a deaf child aged between 4 – 16 years old (see table 3 for demographic information). No further information can be given about the participants as this will increase the risk of each participant being identified.

Table 3.

Demographic information.

Participant ID	Age	Gender	Deaf child's age
P1	40-45	F	10
P2	35-40	F	13
P3	30-35	F	5
P4	40-45	F	16
P5	50-55	F	15
P6	*50-55*	M	15
P7	30-35	F	6

Procedure

Contact with clinical psychologists in two trusts was made and they invited the researcher to their team meeting to talk about the research project. An information sheet (Appendix C) and consent form (Appendix D) were shared with the teams. Clinicians approached the potential families to see whether they were interested (When parents are referred to the service, they tick a box to confirm they are happy to be approached by researchers. Those who ticked the box were approached). If the family was interested, they gave consent for their details to be shared with the researcher. The families were then contacted to obtain their signed consent form electronically. Participants were also contacted a few days before their interview to confirm that they were still happy to proceed. All interviews were conducted online due to coronavirus pandemic. A minor amendment was approved by the university ethics team for the interview to be carried out via an online platform (Appendix E). The move online was in line with NHS/HRA's updated guidelines on how to protect service users and carers during the pandemic (the recommendation was to change to a telephone call or an online platform to conduct an interview). All interviews were conducted individually for up to 118 minutes. Following discussion with the ethics panel, consent was not sought from the child as the research focused on parents' experiences.

Security

The researcher ensured that online security met the requirements of data protection. When a participant joined the video call, the researcher would 'lock the room' to ensure that no-one else could join the meeting. In addition, all interviews were recorded and downloaded to a password-protected laptop.

Interviews

Each participant was interviewed individually on an online platform with a British Sign Language interpreter (BSL). As IPA was used, involving an inductive approach, questions and prompts were used to focus the interview (appendix F). The interview schedule also included background and strengths questions at the beginning to build a rapport with each participant. The broad questions gave the researcher the flexibility to pursue important lines of discussion brought up by participants. Interviews lasted between 62 and 118 minutes. Interviews were carried out over a period of five months. They were recorded using the online platform's recording feature. Interviews were transcribed verbatim, which meant they were transcribed by the BSL interpreter who carried out the interview with the researcher. As transcribed interviews contained confidential information, these were anonymised and kept on a password-protected laptop. Transcripts are stored for ten years.

Data analysis

IPA was used to analyse each interview transcript, and this enabled the researcher to get close to how participants understood and made sense of their individual experiences (Smith et al., 2009). In line with the protocol for analysing data, the researcher followed the steps guided by Smith et al (2009; Appendix G) as shown in table 4:

Table 4.
Steps guided by Smith et al., (2009)

1	Reading and re-reading the transcripts individually
2	Making initial and highlighting comments to develop emerging themes
3	Creating a table with preliminary themes and quotes
4	Superordinate and sub themes were developed by using similar themes by grouping the themes to form other groups.

Quotations from interview transcripts have been selected to highlight the analytic interpretations of the data (Elliot et al., 1999). An audit trail to demonstrate the analysis from the individual level to the final superordinate group is attached (Appendix H).

Quality assurance and reflexivity

A bracketing interview (Appendix I) was held with a deaf researcher who had previously completed a PhD using IPA. This bracketing interview explored the impact of the present researcher's own assumptions and biases. A process of reflexivity regarding the researcher’s motivations for undertaking this research was carried out. The researcher reflected on her lived experience as a deaf person and as a parent to a deaf child. A BSL interpreter was used throughout the interviews, which meant Spoken English was translated into BSL and vice versa. This meant the interpreter had to understand the context before relaying her understanding of the participants’ stories to the researcher. We attempted to stay as close to the participants’ experience as possible throughout the interview.

The researcher also kept a reflective research diary (Appendix J) throughout the process. This was found to be helpful, especially when noting key emotional responses with regards to recruitment processes, interviews and analysis. A few annotated transcripts and a table of developing themes with participants’ quotes were shared with the lead supervisor. This is a part of an inter-coder agreement process to ensure that emergent themes were rooted in the initial data (Yardley, 2008) and to ensure the methodological thoroughness of the data (Smith et al., 2009).

Ethical considerations

Ethical approval was secured through the Health Research Authority (HRA; Appendix K). One minor amendment was approved via the Salomons Ethics Committee. The participants were told about their right to withdraw and confidentiality before the interview. Additionally, they were encouraged to contact the researcher if they had any questions after the interview. It was also discussed and agreed with participants that, although highly unlikely, if they found the interview to be upsetting, a meeting with their care coordinator should be arranged as soon as possible. Lastly, again deemed unlikely, the potential for safeguarding issues to arise due to a disclosure of risk information by participants in relation to themselves or their child was considered.

Results

Three superordinate themes and eleven sub themes were developed that captured the overall stories in each participant's journey. The first superordinate theme is related to their experience of having a deaf child. The rest of the superordinate themes are dual experience of having a deaf child and then a deaf child with mental health difficulties. Table 5 provides a description of superordinate and sub themes along with participants' example quotes.

Table 5.
Themes and example corresponding quotes

Superordinate group	Subtheme group	Quotes
Deafness as a voyage	Impact (or reaction) of the diagnosis	*P5: Yeah, I think, I think it was all of a sudden. It's like he can't hear and all this time we've just ... I mean he slept well and things like that and, you know, all this time thinking that he's been struggling and we felt...I suppose, probably a little bit guilty in a way. Not realizing before*
		P6: I think I was shocked and maybe disappointed.... and trying to try to figure out why this happened. But we don't know"
	Lonely and unknown world	*P3: I've support that I can talk to my friends, but they.. they don't fully understand him and I think some people think oh, well, he just needs to learn to live with it. He just needs to he needs to learn to adapt in this world. Does that make sense*
		P4: So when Sam was diagnosed at they still was in denial again... banging doors and stuff like that. Because Sam was also sensitive to vibrations. So yeah.. on his dad's side of the family completely in denial completely. So that was difficult
Living with uncertainty	Internal conflicts	*P2: Some people would look at Bella and think disability and deaf? And I would think 'what?!*
		P7: You know, you've still got your beautiful child. And yes, they have these like these differences and they have these, you know, what people would call a disability. But to me, it's not really a disability.
	Tensions within the systems	*P2: Now…possibly linked to where we live…it is very difficult. Recently we joined NDCS group but it didn't feel like it was accessible for her."*

		P7: And obviously there was the hearing impaired service team leader .. who cancelled the referrals. Obviously that was a bit of a difficult time for us trusting the team, because she also told us we didn't need to learn sign language because of wanting Andrew to be a hearing child.
	Being a fighter	*P3: I don't want to put him in a box. I don't want him to feel like he has to change who he is to fit into the world.*
		P1: She didn't talk to the right people, like they thought the cochlear implants weren't working and things like that. I knew she talks I was happy. She didn't need the extra pressure on her. I knew she was going ok. I am her mum, I know her.
	Demystifying my child	*P7: we would notice that his behaviour wasn't just unusual, it was quite dangerous... and it wasn't just dangerous to him it was dangerous to other people. Erm.. and so at that point we started to kind of reach out and see you know, where we stood in terms of could there possibly be in issue? We had thought autism and the school had thought possible autism.*
	Wanting to get it right for my child	*P6: We visited erm, obviously, several local schools. And err we we spoke to, obviously, the the teaching staff... and we tried to gauge how much experience, if indeed any experience, they have had of deaf children in their care there.*
		P5: Yeah emotionally it was.. it was probably hard for me erm..being his, you know, Jack's mum. I wanted to get things right for him. And so erm it was always a worry about any decisions you made.
Parenting on another level	The pain of witnessing	*P4: "He's having outbursts more. He's throwing chairs around the classroom because you haven't treated him like a child with a hearing loss.. you've treated him as it is as a fully disabled child.. and fed him sparkles fun and games. And now you want him to work. It's not how a child should.... you should have wanted him to work from day one"*

		P5: So that was a real low point for all of us really. Especially for Jack... and to see him do that to his arms was awful.”
		P3: When he gets frustrated, how can we help him? When he’s happy about something or sad about something erm..when he wants something specific. He he can can’t really explain that to us.”
	Coping with a different child	*P6: Erm..It's it can be hard to accept at times. You know, the one thing that, even now, still disappoints me.. is we can't do all the things that I would have liked my son to do with me. Playing sports.. any sport.. going off and doing all sorts of things ...and it's obviously restricted. That's a bit disappointing.*
		P3: learning the process of learning all of that up until this point has been quite difficult. I'm not sure how to explain (laughs)... I think ...because of his understanding and trying to teach him in a way that he would understand... has been a learning curve for us.”
	Reassurance	*P7: ...Erm and it was, you know, it was just to know about … that well, you know, if she.. if she can.. if she's gone through her whole life without being able to hear, and she's managed to get herself into this kind of profession. It's not that big a deal .. being deaf is not that big a deal at all. It's not going to stop anyone from doing what they want to do and it kind of just gives high hopes for Andrew"*
		P6: “... I think Callum is going to be accepted a lot more than he would have done if things hadn't changed the way they are changing now”
		P3: It's just a more satisfying feeling as a mum. Erm.. that my child is happy. Because you always worry, don't you, with if your child's happy or not happy... or what's going on, especially when he can't tell me. Erm.. So that's that's a really nice feeling, for me..”

	More than just a parent	*P6: I've become a little bit more erm.. I suppose cautious as to what he can do. Obviously you have to be. Erm..you know. I said.. I'd, you know, I'd like to let him do everything but I know we can't. So obviously he can't..he's restricted in what he can and can't do erm...and it's it's... I think personally, as well, because of all the the mental issues he's got.*
		P3: So I'm I'm his security for a lot of things..erm.. most.. most children would become more more independent, but he is very erm..dependent on me to like interpret the world for him…explain things. Obviously, I'm because I'm his mother I understand…erm.. how he explains things so I understand what he's saying. I understand what he wants. And so I explain that to other people for him

Deafness as a voyage

This superordinate theme encapsulates the participants' experience of having a deaf child. They have embarked on a journey into the unknown with their deaf child. This superordinate group has two subtheme groups, which are 'Impact of the diagnosis' and 'Lonely and unknown world'.

Impact of the diagnosis.

The responses the participants had to the diagnosis were an important part of their story. The reactions varied, with some participants experiencing powerful emotions, such as grief and loss. As P1 reflected on her reaction to the diagnosis, she demonstrated a feeling of resentment as a part of her grieving process:

> *" Why Fran? Erm…we look after our children, we fed them properly, we clothe them properly, it was a bit…looking at people…children, what don't get looked after properly and thinking 'why didn't it happen to them?" (P1)*

Participants shared their experience of a range of emotions, and these could be interpreted as splitting, denial and anger. P7 externalising her child's deafness as 'this thing' could possibly be understood as part of a splitting process in relation to the diagnosis. This suggests a powerful emotions of anger, hurt and a sense of feeling powerless. These emotions are considered to be reinforced by many pauses used by this participant:

> *"To be told that he'd had this thing that was going to be with him for the rest of his life..... It just...it broke me heart... it .. like it really did (P7)*

A different experience was described by P3, who did not experience powerful emotions like other participants. Her explanation of not understanding what it would mean is interpreted as denial of the diagnosis. It is possible that P3 developed an unconscious strategy to protect herself from being overwhelmed with emotions at the time:

> *"I think we both kind of thought that it .. mmm ..it would be very similar to raising a hearing child, and obviously we were wrong" (P3)*

Her last words, however, would seem to convey her feeling of guilt and regret for not being more curious about the diagnosis at the time.

Lonely and unknown world.

Most participants had never even met a deaf person, never mind having the knowledge and understanding about how to raise a deaf child. At the same time, the participants discuss their attempt to deconstruct and reconstruct a new identity around what it means to be a parent of a deaf child. Most of the participants had questions that were unanswered at the time as they attempted to search for meanings. The lack of direction contributed to their fear as they started to construct what their new life might look like for themselves and their deaf child:

> *"We've not experienced this and …what.. what what happens to him? You know,'it's... you know, is he different? Is labelled? Does he...? You know at the time it was just like erm.. whether it was the shock of it and thinking what job will he do?" (P5)*

Participants' experience of being "*othered"* is also discussed; if the participants do not share similar shared identities/features with their social systems, then they are more likely to face judgements or pressures from other people. This experience can disrupt their (parents and deaf child) sense of belonging:

> *"Sometime[s] I feel like there is some pressure on us to know some sign language" (P2)*

Some parents developed a need to reach out to people with shared experience/identities as a part of their meaning-making process so that they could reconstruct what their life might look like with their deaf child:

> *"This was a totally new subject to us. And, you know, it was important that if you came across people who had also had experience... it makes a big big difference" (P6)*

Shared experience and developing shared identities were valuable to these participants to ensure that their journey felt less lonely and unknown.

Living with uncertainty

This superordinate theme captures the high levels of uncertainty as the participants' make ongoing adjustments whilst they reconstruct a life as a parent of a deaf child and then when these children develop mental health difficulties. This superordinate theme has five subtheme groups, which are ‘Parenting straddling’, ‘Tensions with the systems’, ‘Being a fighter’, ‘Demystifying my child’ and ‘Making right decisions’.

Internal conflicts.

Participants struggled with accepting their child’s deafness or differences, which is interpreted as an unconscious strategy employed by them to prevent them from feeling anxiety that their child is different. Nonetheless they still use specialist services or charities for their deaf child so that their deaf child can receive specialist support or for them to meet other deaf children.

> *But we don’t see her as a deaf child...we just see her as Fran...erm ’he's...I ’on't know...we just see her as Fran...we ’on't see her as Deaf...” (P1)*

These participants paused a lot between each sentence, and this may be interpreted as a possible reinforcement of the uncomfortableness and anxieties about coming to a realisation that their deaf child is different and experiences things differently. These were understood by research as possible unconscious processes which, while not identified explicitly by participants, appeared to serve a defensive function for self. It was thought that another defence that has emerged was ambivalence, as demonstrated by P2 where she compares her interactions with her deaf child with those she had with her siblings:

> *“So I have never thought she was different…I mean we did singing and signing and things like that, Elizabeth Foundation to support her development but I didn’t feel different with her compared to my other two sons” (P2)*

There is also a possible insight about the reason participants choose to see their deaf child as ‘hearing’ or ‘normal’. They are seeing the traits from their deaf child that the participants identify closely with, such as being able to use ‘speech’:

> *“Jack is Deaf and he's hearing... he's both …. he's both these.. both to us. I suppose we may be seeing more as.. sorry… I suppose we see him more as hearing” (P5)*

Tensions within the systems.

All participants discussed their experience of the stress of accessing services and liaising with professionals for their deaf child and then later for the child’s mental health difficulties. The participants show how they have constructed the concept of ‘support’ in which the professionals are perceived to be the experts. Additionally, because the parents lacked knowledge about how to raise a deaf child with mental health difficulties, they used the professionals as a source for their meaning-making process. However, these participants received much what may be viewed as incorrect advice, and this created a high level of ambivalence towards professionals and the systems, especially when they had to deconstruct and reconstruct what it means to have a deaf child with mental health difficulties. Overall, there is a sense of conflict in that participants appeared to be both grateful to, and angry with, the systems around them:

> *“It’s very oral they told us we should use oral approach and avoid signing so she doesn’t become confused over her language *laughs* we didn’t know any better and followed whatever they told us to do” (P2)*

The bitterness of P2 was, as interpreted by the researcher, shown by her use of laughter as she discussed the incorrect advice given to her by professionals. An insight into the relationship between the professionals and parents is discussed by some participants. This relationship renders some parents powerless and for P7, the struggle between 'mother knows the best' and 'experts know the best' is highlighted:

> *"So someone who sees your child, like once a month or barely even sees them at all. Whereas you see them every single day. It's almost as if they know them better than you..." (P7)*

Because of the perceived power imbalance, there is sometimes a mismatch between parents' and professionals' goals for the deaf child involved. Participants felt that their understanding of their deaf child's difficulties and needs was not being heard by the professionals. This led to high levels of uncertainty and anxieties for the participants, especially in the context of managing their deaf child's mental health difficulties:

> *"Yes .. He's not allowed out on his own at all because he's so vulnerable. But he's not a prisoner. I've said this to Deaf CAMHS and it's wrong for that to be part of his care plan" (P4)*

Being a fighter.

Due to many levels of uncertainty related to the systems, participants who had a child with unmet needs had to develop an identity of being a fighter. The participants discussed the identity as a double-edged sword because in the process of fighting for their deaf child, which is exhausting and mentally draining, they have learnt how to navigate the systems, negotiation skills and confidence:

> *"That... erm... Sam is doing really well because I've got George to bounce off. I don't let the professionals get away with stuff because I'm already invested so much time into the system that I already know what to expect and what should be done." (P4)*

> *"But then since we've had Andrew and we've had to overcome all these sort of obstacles. He hasn't had a voice. I've had no choice but be his voice and to fight for him.. " (P7)*

Other participants adopted a 'fighter' identity for their deaf child within their social systems. Lack of understanding or judgements from others would create disequilibrium in their systems. The function of their fighter identity in this context was to effect a resolution within their systems:

> *"We would get frustrated with that. Like at our dinner table, I could see Bella withdrawing because people are talking at same time. We were trying to stop it and make sure she is included" (P2)*

Demystifying my child.

A constant attempt at meaning making was evident from the interviews with the parents. It seemed to be a bi-directional process, of understanding the present from looking back to the past and making sense of what happened in the past through their experiences in the present. The participants' lack of knowledge of deafness and mental health difficulties created high levels of uncertainty for the parents. They had to deconstruct and reconstruct the meaning of the difficulties their deaf child was experiencing. Some of the parents attributed the difficulties that were occurring at a particular time to their child's deafness:

> *"I don't think at the time that I really did. I think a lot of the things was.. "is he not understanding because he's deaf?"   Is it... a lot of the things probably were more focussed on his deaf …" (P5)*

This would often leave parents feeling frustrated or powerless because of the level of uncertainty in relation to their sense-making journey. The researcher interprets her pause as demonstrating this. This reflected the participants' high level of uncertainties in relation their knowledge of deafness and mental health difficulties.

> *"We're not in not entirely sure...what.. what is CMV and what's his being deaf. Because they're all like linked together" (P3)*

Some participants discussed the interactions between both deafness and difficulties and how these difficulties do not conform with any textbooks. This creates a high number of uncertainties, which in turn contribute to their feelings of powerlessness and helplessness. The participants' experience of sense making is important to them so they can support their child. It is interesting, however, to see that the result of living with these uncertainties are the high levels of resilience and adaptability that are demonstrated by the participants:

> *"We literally had to change the recipe to suit whatever was going on with Barry that week. So just as the recipe ...you thought you'd got it perfect and everything's going smoothly... we'd have to tweak the recipe the following week" (P4)*

Wanting to get it right for my child.

All participants expressed a desire to get it right for their deaf child. Participants discussed the feeling of having no control regarding the outcomes of their decisions, which have been inconsistent to date. This has contributed to a sense of intolerance of uncertainty for the participants:

> *"But I do say to my husband a lot... I really worry that we're not doing a good enough job with him, and we don't understand them well enough..." (P3)*

The implicit and explicit discussions regarding responsibilities and uncertainties as unwanted burdens have taken a toll on participants. P5 discusses her experience of being fraught with worries about whether she has made the right decisions:

> *"it was probably hard for me erm..being his, you know, Sam's mum. I wanted to get things right for him. And so erm it was always a worry about any decisions you made" (P5)*

Hindsight is the ability to understand a situation after it has happened; but it can help you make better decisions in the present. There is a sense of regret across the participants due to 'wrong' decisions made in the past based on flawed advice. It is part of their sense-making process that the decisions made may have contributed to the difficulties their deaf child is currently experiencing:

> *"If we know now what we knew then, we would have had cochlear implants plus sign language early to support her" (P2)*

Parenting on another level

This superordinate theme captures the management of participants' multi-faceted identities, such as being a carer or a teacher to support their deaf child with mental health difficulties on a day-to-day basis. In parallel with this identities development process, the participants are also carrying a lot of grief and emotions. This superordinate has four subtheme groups, which are 'The pain of witnessing', 'Coping with a different child', 'Reassurance' and 'More than just a parent'.

The pain of witnessing.

All participants feel strong emotions of powerlessness and helplessness, and sometimes anger. These emotions are linked to their difficulties in relation to sense-making regarding their deaf child's difficulties. This have contributed to them not being able to develop coping strategies. Thus, participants discussed their attempt to carry their deaf child's pain instead. The emotional impacts of witnessing their child in pain are illustrated by two participants:

> *"She hadn't spoken all day...the tantrums were terrible. She was pulling her hair...You could just see the frustration ..it must be so hard to not speak all day..." (P1)*

> *"We would get frustrated with that. Like at our dinner table, I could see Bella withdrawing because people are talking at same time." (P2)*

An insight into why the participants find it painful when they witness their deaf child's suffering is discussed. Some of the participants have framed their child's deafness as a burden that participants themselves and their child have had to carry. This is already difficult for the participants to accept. Now, with the additional difficulties these deaf children have developed, they are carrying even more. This provokes strong emotional pain within these participants as they witness their child's sufferings:

> *"Because he's not only got the deafness to contend with, but now he's got even more issues" (P6)*

Coping with a different child.

Being reminded constantly that their child is different is a bidirectional process as the participants look into the past and into the future. The reminder can trigger the grieving process or reopen a wound that has not yet been resolved. The participants tend to compare their deaf child to their siblings or receive unhelpful comments from other people.

In the context of mismatched support, the participants tend to struggle with the extra responsibilities and burden of managing their deaf child's mental health difficulties. This is evidenced by P4's discussion about her child being called a *"cupcake child"* because he does not fit neatly into a box. This means the participant and her child fall short of support that can be provided to them and contributes to her use of the language of feeling stuck. This creates more difficulties for the participant to reconstruct a path forward:

> *'There's like in this like a no-go Zone. It's like a no-man's-land zone (laughs) between the two. You either are or you're not and then Sam fits a lot in the no go zone. So they actually call Sam a cupcake child" (P4)*

In the context of grief, the constant reminder of difference contributes to the participants' chronic grief in relation to their deaf child's difficulties. This participant's use of *"perfect"* to describe his deaf child's sibling reflects his grief and his difficulty accepting his deaf child's differences.

> *"Well Emma.... She has.... she has no issues whatsoever regarding her health. And she was all most.. dare I say ...she was almost the perfect child growing up.." (P6)*

The participants are reminded daily that their deaf child has extra difficulties that they are struggling to understand. As a result, they feel a range of emotions, including grief, helplessness and resentment. P7 demonstrates that by externalising blame towards her deaf child as she grieves for the life she will never have:

> *"it's that.. it sounds awful to say he spoils it. Because he's just a child and you shouldn't sort of blame him. " (P7)*

Reassurance.

This subtheme captures the reassurance given to these participants as they attempt to manage their deaf child's difficulties. Due to feeling stuck or/and hopeless, these parents have a need of being reassured by other people. The reassurance gives participants a will to carry on whilst juggling feelings of being a failure, powerlessness and helplessness simultaneously. These two participants demonstrated that being reassured by professionals is helpful to keep them going:

> *“I don't don't get things right. But yeah, I think it's just that reassurance from Daisy saying “Yes, don't take it all on your shoulders. And at the end of the day you are doing a great job as parents”(P5)*

> *“They gave me confidence that I didn’t miss anything and that I was doing it right and giving Fran the support too” (P1)*

For some participants, seeing progression in their deaf child, especially in the context of high stress and uncertainty, gave them some reassurance that they were on the right path and that they were doing enough for their child:

> *"It's just a more satisfying feeling as a mum. Erm.. that my child is happy. Because you always worry, don't you, with if your child's happy or not happy... or what's going on, especially when he can't tell me...” (P3)*

More than just a parent.

This subtheme captures the identities that these participants had to develop as a part of their sense-making journey. The functions of these identities are to manage the difficulties by using problem-solving approaches. These two participants discussed their role as a parent where they had to do extra teaching to ensure that their deaf child could navigate in the hearing world more efficiently:

> *"I thought I could learn what she was learning and then we can talk about it at home as well. Because her brain functions differently from the hearing child" (P1)*

> *"We have never had to teach the boys about the sounds but we have had to teach Bella about the sounds out there….like where did the sound come from, we had to teach that to her"(P2)*

Participants who are carrying the burden of these identities are also experiencing a loss of their parent identity. Thus, they interact with their deaf child differently than with their hearing siblings, as explicitly discussed by P4. She found the burden of the responsibility very difficult to manage and she did not have any capacity to be a parent to her deaf child with mental health difficulties:

> *"It's really difficult because I feel I'm not Sam or George's parents. I predominantly feel I'm their carer. There is this barrier between us ... (P4)*

Discussion

The aim of this study was to explore how hearing parents make sense of their experience of having a deaf child who is experiencing mental health difficulties. The findings highlighted the dual experience of having a deaf child and then a deaf child with mental health difficulties. As a result of this, the participants had to deconstruct and reconstruct how they have understood their deaf child and then their deaf child with mental health difficulties due to flawed information and high levels of uncertainties.

They embarked on a new and unknown journey when their child was diagnosed as deaf and then a further journey into the unknown when their deaf child developed mental health difficulties. The unknown, uncertainties and not being acknowledged by others have contributed to the loss and ambiguity experienced by the participants. All participants have grieved, and they are still grieving on some level due to unresolved grief and ambiguous loss. This is supported by a study which suggests that the grieving process by hearing parents can take up to 20 years (Flaherty, 2015). Young (1999) put forward the idea that the grief theory is deeply rooted in a medical model of deafness. The model views deafness as a deficit and an anomaly versus what is typical for most of the population. This finding is reflective of what the participants in this study shared with regards to the loss of their ‘perfect’ child. As discussed, grief can occur in responses to stressful events, health crises and unmet developmental milestones (Flaherty, 2015). This aligns with the participants’ experience when they witnessed their deaf child’s suffering when they developed mental health difficulties. In line with the current literature, as their deaf child is still physically present but may be psychologically absent due to mental health difficulties, the parents’ re-experiencing grief can be described as “ambiguous loss” (Boss & Yeats, 2014).

When a participant’s child was diagnosed as deaf, the news shifted their way of living to the point that they lost the ‘map’ which was guiding their lives (de Melo, 2020) in the way they had known. However, participants discussed several levels of uncertainty, related to a lack of shared experience, direction, and information post diagnosis. This meant that the reconstruction process to create a new ‘map’ was difficult for many participants, and this created a high level of stress and a sense of feeling powerless. Analogical processing, which is using your knowledge from previous situations to infer new information in another situation, helps with people’s sense-making process and as a result of this, the reconstruction process can occur (Williams, 1984). Due to the unknown, one could argue that the parents were unable to draw on an analogical processing strategy, and instead had to rely on assimilating new information about how to raise a deaf child from professionals or parents with similar identities in order to reconstruct a new life. As highlighted by participants, the information shared can be incorrect This meant they had to repeat the whole deconstruction and reconstruction process when their deaf child did not meet their developmental milestones and when they developed further difficulties, with their mental health, that the parents had not foreseen.

There is a systemic review that looked at the decision-making process of hearing parents of deaf children (Porter et al., 2018). Parental values and beliefs were the two factors that influenced their decision making. This is based on their ‘old’ map of living, which has been shattered by the diagnosis, they relied on the information received by medical professionals. This is in line with Young (1999)’s study where it was found that the models of understanding deafness have an impact on parental decision-making. However, the participants discussed the inconsistent outcomes of their decisions, and this contributed to high levels of uncertainties and stresses experienced by them. The high levels of uncertainties and stresses are reflective of the current literature in relation to parents’ emotions when managing a child with disability or mental health difficulties (Brown, 2018; Reiss et al., 2019). The difficulties in relation to decision making process are reinforced further when the participants discussed their inability to demystify their deaf child with mental health difficulties as they do not conform to the textbooks. As a result of their lack of knowledge, many of the participants and professionals had incorrectly attributed some behaviours to deafness, which meant late diagnosis, support, and interventions when the deaf children developed further difficulties.

The participants discussed their ambivalence in accepting their child's deafness and their mental health difficulties because of their fear of difference. Due to the ambivalence feeling experienced by these participants, one could argue that they have employed unconscious adaptive strategies to manage their anxiety and other unmanageable emotions. It is considered that these participants demonstrated a few unconscious ways of coping with this ambivalence. Defences are thought to become activated when anxiety feels too strong. One of the defences, splitting, is described as both love and hate for the same object (Klein, 1935). This is evidenced specifically by P7's account where she externalised her child's deafness as 'a thing' and attempted to reject it. This is in line with Young (1999)'s study where she reported that hearing parents had accepted their child but not their deafness. In addition to this, Young (1999) found that if hearing parents come to a full conscious realisation that their child is deaf, this would mean them accepting that there are things they could not know about their own child. One might argue that this is an anxiety-provoking concept for hearing parents. This is reflective of the interpretation of the participants' accounts of 'internal conflicts' where they are experiencing feelings of being conflicted between hearing/normal and deaf/not normal.

In relation to the participants in this study, there is a lot of ambivalence in their relationships with professionals and the systems, especially when there are a lot of uncertainties surrounding their deaf child's needs in relation to their deafness and then mental health difficulties. As the participants lacked knowledge and skills in how to bring up a deaf child, the findings demonstrated that many of them are positioned to be 'passive' either by themselves or the professionals, which is described by Case's (2000) expert model. In relation to the reconstruction process, the participants also tried to make sense of their deaf child and their difficulties through the professionals. As there is still a lot that remains unknown within the professional world in relation to what it means to be deaf with co-existing mental health difficulties, parents received wrong or conflicting information from the professionals. This is aligned with current research about professionals' lack of knowledge in relation to deaf children (Humphries et al., 2014; Hall, 2018). This contributed to the emotions of anger and bitterness in the participants, especially when the implications of the advice were not known until many years later. The impact of this for the participants is increased stress and uncertainty for the future, and this is supported by Quine & Rutter's (1994) and Flaherty's (2015) studies above.

In response to the unmet needs in the context of uncertainties, the participants felt forced to fight for their deaf child with mental health difficulties and these participants showed high levels of resilience and adaptability. Whether or not parents choose to be advocates for their children may be related to their level of empowerment as they become their deaf child's voice. The process of developing empowerment involves determining one's own personal power and the ability to take control over one's life (Wright & Taylor, 2014). Self-efficacy is also considered to be an important part of the empowerment process, as demonstrated in some participants. However, in the process of being a fighter, some participants reported feeling a loss of identity. This is reflective of the current literature in relation to the loss of identity in parents with a child with disability. They reported that they lost a sense of who they were in trying to deal with the responsibilities of caring for their child's needs (Helitzer et al., 2002; Whicker, Munoz & Nelson, 2019). This aligns with the participants' stories, especially these who found it difficult to be a parent to their deaf child.

The medical model is designed to focus on the 'impairment' part of the individual and it implies that the person cannot be equal because of that impairment part (Putnam et al., 2022). The model implies that deaf children with mental health difficulties may have ‘double deficits. In other words, it means that these children are experiencing ‘double stigma’ and this stigma can be attached to their parents too (Niedbalski, 2023). This can disrupt their sense of belonging in the society, which some participants have described as the feeling of not being understood and not knowing where they belong in their social world.

Many of the participants appeared to be powerless and helpless in some contexts and for them to have hope for their deaf child, the hope had to be ‘inserted’ into them. Synder et al., (1991) proposes that hope is related to an individual’s ability to develop a ‘pool of strategies to reach their destination’. This theory implies that the participants do not necessarily have skills or the understanding to develop strategies to overcome difficulties they are currently facing. This is not surprising due to the participants’ lack of knowledge in relation to their deaf child with mental health difficulties. This is in line with literature that demonstrates that the level of hope in parents of a disabled child is lower than parents of typically developing children (Rostami et al., 2014; Calderon & Greenberg, 1999)

Limitations

The sample size is small and is from only two NHS trusts so the experiences of the participants within this study may not be representative of what other parents are experiencing with their deaf child. In addition, the participants were based in different NHS Trusts, meaning the context and the type of support they received may have been different. The evidence for there being a “postcode lottery” (Nuffield Foundation, 2021), in relation to support for deaf children suggests that there are inconsistent levels of support across the country for deaf and disabled children. It is not clear whether context would have made a difference to participants’ experiences. However, given that the sample was drawn from a small and dispersed population, this was unavoidable.

The wide range of ages of the children in the study may have impacted the parents’ view about their deafness and subsequent mental health difficulties differently. It is possible that parents with recent diagnoses are still processing their own grief. Other factors that may be different due to the wide range of ages are related to professional advice and feeling betrayed later on in their deaf child’s life, especially when oral language was pursued (Gregory, 1995). Some parents may have carried their own guilt differently, especially those parents with a child with acquired deafness; they may blame themselves more for their own perceived inactions (Shezi & Joseph, 2021). In addition, it is possible that each child’s mental health difficulties present differently; children who are younger are more likely to have behavioural difficulties whereas older children are more likely to have emotional difficulties. Consequently, the experiences described here may be specific to these participants, and care must be exercised in making any generalisations beyond this.

A further limitation is that all participants but one were female, which may mean that this study may not reflect parents’ experience in general. As with all qualitative research, the results are not expected to be fully generalisable but the research aims to demonstrate the importance of working with hearing parents to understand how they make sense of their experience.

Lastly, the research was influenced by the researcher who is deaf and is the parent of a deaf child. My experience will have affected both the data obtained and the outcome of the analysis. I have my own beliefs and assumptions about hearing parents’ beliefs, values, and choices they have made for their deaf child and in relation to their subsequent mental health difficulties. During interviews and the analysis process, I was acutely aware of my position, and views, and worked hard to act as an impartial observer to their lived stories. It is possible that participants responded to the researcher differently than they would have to a hearing researcher. Although quality measures were used to reduce issues of interpretation, including discussion of themes with the supervisor, the double hermeneutic nature of IPA recognises that the findings are based on an interaction of my lived experience and my own perspective with their lived experiences. In other words, the influence and biases of my position may have limited the analysis, interpretation, and the generalisability of the results.

Clinical implications

The ambiguous loss experienced repeatedly by the participants in this study highlights how important it is for the clinicians to be mindful of unresolved feelings of grief and pain for hearing parents, even if a diagnosis of deafness and/or mental health difficulties was made many years earlier. The grief experience can be reduced by meaning making (Boss, 2006), but participants, evidently, struggled to make sense of their deaf child with mental health difficulties. Thus, the focus should be on supporting these parents to increase their resilience around the uncertainties arising from their deaf child’s difficulties.

For some of the hearing parents who are feeling helpless and hopeless due to their inability to make sense of their deaf child’s difficulties, Boss’ (2006) suggestions for therapeutic interventions could be useful, such as ‘tempering mastery’ and ‘reconstructing identity’ or developing skills and strategies using solution focused approaches. These interventions include externalising blame; identifying past competencies that are transferable and providing a space for them to develop strategies. The aim of these interventions is to encourage the parents to feel as though they are “choosing to accept and live with the uncertainties rather than continuing to perceive oneself as being the helpless victim of it" (Boss, 2006) and being able to navigate the unknown world with their deaf child with mental health difficulties. In the process, the need for hope being 'inserted' by external factors will hopefully reduce and lead to an increase in self-efficacy skills in these parents.

It has been established that providing parents with a space to tell their stories is likely to lead to improved outcomes (Carter et al., 2007). However, this can often be difficult to schedule in busy NDCAMHS settings. It is worth considering the use of groups on an online platform for parents to share their experiences with each other, with a NDCAMHS clinician facilitating the group. It could be helpful for those parents who are struggling to make sense to hear from those who have constructed some positive meanings, which would allow for a shared story to be developed and reduce any possible attached stigma. It is hoped that this will increase their sense of belonging within their social world. The facilitator could also provide some education on deafness and mental health difficulties using the latest evidence-based research. Additionally, narrative therapy techniques can be used to invite these parents to create alterative stories about themselves and their deaf child (Waugh 2004). This is supported by some of the participants who valued their experience of meeting other parents with a deaf child. Not having opportunities to meet as a group has been shown to perpetuate powerlessness (Cooke et al., 2015) and that having a shared space for these parents can be empowering, which may reduce the feeling of hopeless and increase their self-efficacy skills.

Research implications

Future research may wish to explore a different client group, for example, deaf children with mental health difficulties and how they make sense of their experiences. Another interesting area to research would be whether the way in which hearing parents construct their deaf child's difficulties impacts on a deaf child's wellbeing and recovery.

Additionally, future research would benefit from testing the hypothesis that the interventions discussed in the clinical implications section (pg.34) would reduce emotional distress for the parents of deaf children with mental health difficulties. The outcomes of this study suggest that some of these hearing parents may benefit from interventions aimed at encouraging meaning making and developing coping strategies. Identifying appropriate interventions and evaluating their efficacy for these hearing parents should be prioritised.

Finally, it is hoped that this study will help clear the way for more research that aims to develop more positive and meaningful narratives for parents.

Conclusions

In summary, this study has shown that parents make sense of their deaf child's mental health difficulties in a variety of ways. Ambiguous loss can be used to describe the participants' experience of having a deaf child with mental health difficulties (Boss, 2006). As they are on a journey into the unknown, these parents have struggled to make sense of their deaf child and their mental health difficulties, especially in the context of high levels of uncertainties. Their turbulence process of deconstructing and reconstructing and flawed information has left many of them feeling hopeless and powerless. Lastly, it is hoped that this research has shown that parents of children with mental health difficulties are likely to need support alongside their children.

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Appendix C: Information Sheet

Information Sheet

How parents' make sense of their deaf child's mental health problems

Hello. My name is Josie Smith and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether you would like to take part, you will need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. If you would like further information or if anything is unclear, then please contact me.

What is the purpose of the study?

The purpose of the study is to develop an understanding of the experience of parents with a deaf child with mental health problems. There is a need for a deeper understanding of how to work with parents of a deaf child with mental health problems. This in turn can inform the clinical psychologists and other professionals involved on how to work with parents and their deaf children to improve the children's wellbeing.

Why have I been invited?

You have been invited to take part in the study as your child has been referred to National Deaf Child and Adolescent Mental Health Services (NDCAMHS). We will be asking all parents involved in the services to take part in this study which is entirely voluntary. This means it is up to you to decide if you would like to take part. Participation is voluntary and choosing to take part/not take part in this study will have no implication on the service you and your child receive from NDCAMHS.

Who is conducting the study?

The study will be conducted by Josie Smith; a trainee clinical psychologist based at Canterbury Church University. The research is funded by Canterbury Christ Church University and is being supervised by Dr Alex Hassett (Canterbury Christ Church University). This research project forms part of doctoral studies in Clinical Psychology.

What will I be asked to do?

We will ask you to sign a consent form to demonstrate your willingness to take part. Participating in the study will involve you taking part in an interview with me. The interview would last approximately one hour to one and half hour. You would only need to meet with me once. The interview will be conducted via online platform (Zoom).

There will be a British Sign Language (BSL) interpreter with me because I am profoundly Deaf and a BSL user. All interpreters I use are part of National Registers of Communication Professionals with Deaf and Deafblind people. This means they have been checked for their professionalism, criminal records and to ensure that they follow the ethics guideline and code of conduct, including confidentiality. Additionally, the interpreters I will be using have some experience of working in mental health settings. If you would like to ask me questions about this, please do not hesitate to contact me using my email address below.

During the interview, I will ask you some questions about your child and how it has felt for you and your family to be told that your child is deaf and has mental health problems. I will need to record the interview so that I can document what we talked about. When I type it up, I will remove any information that would identify you or your child, such as names, places and dates. If you would like to see a copy of a transcript to confirm I understood you correctly, I can post or email you a copy, or I can arrange a phone call to discuss this with you.

Your decision on whether or not to be involved will not affect your child's care from the National Deaf
CAMHS team; this will continue as usual.

Expenses and Payments

You will be paid expenses for your travel to the interview, up to a value of £10.

What are the possible disadvantages and risks of taking part?

Although there are no obvious 'risks' of being involved in this research, I will need to ask you to think about whether you would feel comfortable talking to me about your child's deafness and mental health problems. Please also think about whether you feel you would have the time available to come for the interview.

You may feel that it is helpful to talk to me about the experience of having a deaf child who has mental health problems. I will not be able to offer you advice during the interview, but if you have any questions following the interview, I will ask your child's care coordinator to contact you. We cannot promise the research project will help you but we hope that the information from this research project will help us develop a better understanding of the experience of parents like yourselves which may in turn lead to service improvements.

What if there is a problem?

If you have a concern about any aspect of this study, please email me at: j.l.smith1002@canterbury.ac.uk and I will do my best to answer your questions. If you remain unhappy and wish to complain formally, please contact Dr Alex Hassett at Canterbury Christ Church University on 0333 011 7093 or email at alex.hassett@canterbury.ac.uk.

Will my information be kept confidential?

Yes, all your information will be kept confidential. I will not have access to your child's care records during the research. I will only share information from the interview with a member of your child's care team if I have a concern your child's (or anyone else's) safety. Usually, I would discuss this with you first.

All information from your interview will be made anonymous – this means that I will take out any information that would identify you or your child, such as names, places and dates. Anonymous transcripts of the interviews will be stored on an encrypted memory stick and then kept in a locked cabinet at the university for 10 years after the research is finished. After this point, it will be destroyed. The information will not be used for any other research projects.

What will happen if I don't want to carry on with the study?

You can decide at any point before or during the interview that you no longer wish to take part in the study. If you decide you no longer wish to take part, all information collected from you will be removed from the research. You are not required to have any further involvement in the research after the interview.

What will happen to the results of the research study?

The results of the study will be written up into a research project, which will be available to clinicians working with families. We intend to publish the results of this study in an academic journal. Quotes might be used in the write up, but these would be made anonymous, so that you could not be identified from them.

You will be given the option of seeing the results and/ or a transcript of the interview before the project is completed and giving your comments. If you would rather, a summary of the results can be sent to you after the project is complete.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by Wales REC 6 Proportionate Review Sub Committee.

Further information and contact details

If you would like to speak to me and find out more about the study or ask any questions, you can email me at j.l.smith1002@canterbury.ac.uk. I will reply as soon as I can.

Appendix D: Consent form

Consent form

Title of research: *How parents' make sense of their deaf child's mental health problems*

Please circle as appropriate

I confirm that I have read and understood the information sheet for this study, dated 22.06.2020. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

Yes No

I understand that my participation is voluntary and that I am free to withdraw at any time without needing to give a reason. This will not affect mine or my child's medical care or legal rights

Yes No

I agree to take part in the study, which will involve a one off interview approximately 60-90 minutes in duration, with a researcher from Canterbury Christ Church University. During the interview, I will be asked about the experience of having a deaf child with mental health problems. I will also be asked to talk about when my child's deafness was diagnosed and what happened afterward. I agree to this interview being video and audio recorded.

Yes No

I understand that the information I give will remain anonymous and will not be shared with the CAMHS team, unless I say anything which suggests myself, my child or another person is at risk of harm.

Yes No

I agree for anonymous quotes from the interview to be written up and published. My name and other identifying information will not be included.

Yes No

Tick the box if you would like to receive a summary of the results ☐

Name of parents:

Parent signature Date:

Appendix E: Amendment approval (email)

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Appendix F: Interview schedule

Semi-structured interview schedule

Points to cover before commencing interview:

- Thank you for coming today and for agreeing to take part in this interview. As you know, I will be asking you about your child, their deafness and difficulties and how this has felt for you. Do you have any questions before we start?
- Have you worked with an interpreter before? If not then explain how it works. I will sign to you and the interpreter will watch what I am saying whilst voicing over for me. When you speak, the interpreter will listen whilst signing what you're saying. Do you have any concerns about working with an interpreter before we start?
- As I explained on the phone, I would like to record today's interview so that I can remember everything we talked about. I will then type up our conversation, and I will remove any information that might identify you, such as names, places and dates.
- Go through consent form with participant and sign – explain information about withdrawing, confidentiality etc
- The interview will last approximately one hour to 90 minutes. If at any point you would like to take a break, just let me know. If there are any questions you don't understand, or that you would rather not answer, we can discuss these together. If at any point during the interview you want to stop, just tell me and we can end the interview.

General:

I would like to begin by asking you some questions about your child. Tell me about (name)?

Prompts:
a) What are some of the things that (name) likes? What is s/he good at?
b) What things s/he doesn't like? What things does s/he find difficult?
c) Are there any ways in which s/he is similar to or different to other children their age?

Deafness:

What does the term 'deaf' [or other term you use] mean to you?

Can you tell me about when you were told that your child was deaf?
a) What was your understanding of what it meant?
b) What were your views/feelings during this time?
c) Is there another way you might have explained/thought about your child's deafness?
d) How did others react? (e.g. family, friends, the other parents)

Can you tell me about your experience of having a child who is deaf?
a) Has anything changed?
b) What is your understanding of what it means?
c) What were your views/feelings of having a deaf child?
d) How do you explain it now?
e) What is it like for you now?

Can you tell me what you think it is like for your deaf child growing up in a hearing family?
a) What is your understanding of what it means for the child
b) What is your feelings about it?
c) Has anything changed?
d) Views/feelings of wider family/friends/other parents?

Mental health problems:

What does the term ‘mental health problems’ [or other term you use] mean to you?

I understand your child has been referred to National Deaf Child and Adolescent Mental Health Services. I would like you to think back before the referral process started, tell me about when you first noticed something was different?

- **a)** Who first noticed the change in her/him?
- **b)** What were your views/feelings at this time?
- **c)** How did you explain this at the time?
- **d)** Views/feelings of wider family/friends/the other parents

Can you tell me about about [name]’s mental health problems?

- **a)** What is your understanding of what it means?
- **b)** What are your views/feelings about it?
- **c)** Views/feelings of wider family/friends/the other parents

Deafness and mental health problems:

What is your experience of having a deaf child with mental health problems?

- a) What is your understanding of what it means?
- b) What are your views/feelings about it?
- c) How do you explain it now?
- d) Is there anything you would do differently?

Can you tell me what you think it is like for your deaf child to have a mental health difficulty?

- a) What is your understand of what it means?
- b) What are your views/feelings about it?
- c) Views/feelings of wider family/friends/the other parents?

Can you tell me about how you have experienced the assessment/therapy process at NDCAMHS?

- **a)** What was your understanding of what was happening?
- **b)** What were your views/feelings during the assessment?
- **c)** What were your views/feelings during the therapy?
- **d)** Has your child being here had any effect on how you see the family?
- **e)** What are your hopes from NDCAMHS?

AOB

Is there anything else you would like to say in relation to anything we have talked about today?

Appendix G: The steps guided by Smith et al (2009)

1. The first stage involved reading and re-reading the individual transcripts to gain familiarity with the data.
2. The second stage involved making initial comments and highlighting comments that the researcher felt were important and relevant. The researcher used the right-hand margin for explanatory notes or comments that were felt to be meaningful to the participants and were related to the research questions. The emerging themes were noted using the left margin. These were transferred to a separate document.
3. A table was created with preliminary themes for each individual and some quotes that the researcher felt reflected and stayed close to the participants' experiences (appendix x).
4. Superordinate and sub themes were developed by using similar themes. These were grouped together to form other groups (appendix x).

Appendix H: Sample of P7 coded transcript

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Appendix H: A sample of emergent themes from individual level

P5
Emotional impact of the diagnosis
Concerns from others
No space to process
Different behaviours
Adjustment process
Meaningful support

Difficulties are masked
Guilt
No experience of deafness
Unknown
Different parenting
The impact of communication on my child's behaviours
Process of understanding
Witnessing suffering

Identities are merged
Shared experience
Meaningful support
Meaning making
Future uncertainty
No progressions
Process of decision making

P6
Not normal
Fear of difference
Concerns from others
Emotional impact of the diagnosis
Seek out for information
Future uncertainty

Witnessing suffering
Fear of difference
Process of understanding
Loss of ‘perfect child’
Old vs. new beliefs

Behaviours from others
Future is unknown
Feeling lost

Unanswered questions
Meaningful support
No support
Time consuming
Lack of understanding from others
Process of understanding
Reassurance

P7
Long journey
Emotional impact of the diagnosis

Loss of perfect child
Loss of ‘perfect’ life
Loss of mother role
Unknown
No experience of deafness

Denial of the diagnosis
Diagnosis is uncertain
Unknown future

Relationship barrier
Unanswered questions
Confusion

Awareness of difference
Grieving
Meaningful support
Information sharing
Meaning making
Lack of understanding from others
Adaptive parenting

A sample of group themes on an individual level

P1
No space to process
Survival mode
Overwhelmed
Family commitments

Negative emotions
Resentment
Guilt
Shock

P2
Power imbalance
Passive role
Professionals are the expert
Trust
No experience of deafness

Straddling
Different vs. Normal
Not seeing the deafness
My child is not the same as others
Specalist support

P3
Unknown
No experience of deafness
Not understanding deafness
Lack of understanding from others
Not understanding the diagnosis

P4
Understanding my child
Delayed milestones
My child is different
Meaning making
Comparisons

I am a fighter
Unmet needs
Not being listened to
Knowing the system
Doing the work

P5
Negative emotions
Guilt
Upset
Shock
Fear

Normal vs. different
Witnessing difference
My child is hearing
Comparing siblings

P6
Unknown
No experience of deafness
Seek out for shared experience
Lack of understanding from others
Unanswered questions

New vs. old beliefs

What it means to be different
Others' understanding
My experience of difference
More acceptance

P7
Unknown
No experience of deafness
Future uncertain
Lonely and lost

Fighter
Unmet needs

Not being listened to
Life skills

An example of subtheme and superordinate themes development

Super ordinate theme	Subtheme	Emergent themes	Number of people themes were applicable to
Deafness as a voyage	Impact of the diagnosis	*Emotional tolls,* *No space to process* *Losses*	*6*
	Lonely and unknown world	*No experience of deafness* *Alienation by others* *Unanswered questions* *Seek out for shared experience*	*7*
Living with uncertainty	Parenting Straddling	*Internal conflicts,* *Using specialist services,* *Deaf vs. hearing* *Normal vs. different* *Tensions between old and new beliefs*	*6*
	Tensions within the systems	*No support vs. Support that does not work, expectations,* *Lack of information* *Flawed advice* *Not aligned with professionals*	*6*

	Being a fighter	*Double edged swords – emotional impact & skills learnt* *Unmet needs* *New identity*	*6*
	Demystfying my child	Meaning making, Interactions of all difficulties, Attributing difficulties to his deafness	*6*
	Wanting to get it right for the child	*A desire to get it right* *Not knowing how to help* *Responsibilities are a burden* *Process of decision making* *Hindsight*	*6*
Parenting on another level	The pain of witnessing	*Changing relationship* *Powerless* *Not understanding* *Lack of strategies*	*7*
	Coping with a different child	*Constant reminder* *Emotional tolls* *Not conforming with textbooks*	*6*

	Reassurance	Hopeless Professional involvement Keep going	*6*
	More than just a parent	Multiple identities Loss of identity Problem solving approaches	5

Appendix I: Bracketing Interview

1. **Pre-interview**
2. How did you come to undertake this research?
3. What do you think are the similarities and differences between yourself and your participants?
4. How are you feeling about this research as a deaf person and a mother to a deaf child?
5. Why do you *think* (or assume) people might take part in your research?
6. What do you hope will come of the research? What impact do you hope it will have?
7. Have you felt anxiety/annoyance or enjoyment at any point so far?
8. How do you hope your interviews will go? Are there things you hope to hear? Or don’t want to hear?

Appendix J: Reflective diary excerpts

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Appendix K: Ethical approval

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Appendix L: End of study summary for HRA

Hearing parents' experience of having a deaf child with mental health difficulties: An Interpretative Phenomenological Analysis

I am writing to notify you of the completion of the above research study. This study has been written as a thesis for submission in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology. A summary of the study has been included below.

Introduction

Over ninety percent of deaf children are born to hearing parents (Ahmad et al., 1998). Most of these parents have no prior experience of deafness (Marshark et al., 2018). The parents may be overwhelmed with acquiring new knowledge, learning how to adapt in interaction and communication with their deaf child and navigating the personal and familial process of adjustment for the family (Young 2010; Young & Russell, 2016) whilst grieving for the child they never had.

The research has demonstrated that up to 65% of deaf children will experience mental health difficulties compared to 15% of hearing children (Brown & Cornes, 2015). Most of deaf children with mental health difficulties come from hearing families (Hintermair, 2006). The current research has consistently demonstrated that deaf children of deaf parents outperform deaf children from hearing families in language, academic functioning, and psychosocial adjustment (Hadadian & Rose, 1991; Ritter-Brinton & Stewart, 1992; Harris, 2001). Additionally, Musselman (2000)'s study demonstrated that deaf children of deaf parents thrive because of a fully and naturally accessible language environment. Deaf parents also demonstrated a high level of knowledge, acceptance and preparedness to raise a deaf child.

There is no research to date that explores hearing parents' experience of having a deaf child with mental health difficulties. This study was felt to be important in addressing a unique gap and to extend the current literature. It is also critical to understand hearing parents' lived experience of their deaf child's mental health difficulties as well as highlighting what support may be needed for them.

Aim of study

This study aimed to address the following research questions:

1. How do hearing parents make sense of their deaf child's mental health problems?

2. What are hearing parents' experiences of having a deaf child with mental health problems?

Method

Semi-structured interviews were conducted with 7 hearing parents about their experience of having a deaf child with mental health difficulties. Interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA). IPA is primarily concerned with participants' sense-making of their experiences and the meanings specific experiences hold for them (Smith, 1996).

Results

Three superordinate themes and 13 subthemes were derived from the analysis. The superordinate themes are: The deafness as a voyage, Living with uncertainty and Parenting on another level. A summary of the superordinate themes and subthemes, including illustrative quotes, are presented in the table.

Superordinate group	**Subtheme group**	**Quotes**
Deafness as a voyage	Impact (or reaction) of the diagnosis	P1: " Why Fran? Erm…we look after our children, we fed them properly, we clothe them properly, it was a bit…looking at people…children, what don't get looked after properly and thinking 'why didn't it happen to them?"
	Lonely and unknown world	We've not experienced this and ...what.. what what happens to him? You know, it's... you know, is he different? Is he labeled? Does he...? You know at the time it was just like erm.. whether it was the shock of it and thinking what job will he do? Er.. how will he cope with his friends at school" (P5)
Living with uncertainty	Parenting Straddling	"So I have never thought she was different…I mean we did singing and signing and things like that, Elizabeth Foundation to support her development but I didn't feel different with her compared to my other two sons" (P2)
	Tensions within the systems	It's very oral they told us we should use oral approach and avoid signing so she doesn't become confused over her language *laughs* we didn't know any better and followed whatever they told us to do (P2)
	Being a fighter	So I always go... "I've got another child already done XYZ with.. so you cannot railroad me with this child ..this is what's happening....This is what we're doing" (P4)

	Demystfying my child	So I think a lot of... a lot of things like “is it because he's Deaf?” You know, we kept going back to that” (P5)
	Wanting to get it right for my child	I really worry that we're not doing a good enough job with him, and we don't understand them well enough (P3)
Parenting on another level	The pain of witnessing	because he's not only got the deafness to contend with, but now he's got even more issues (P6)
	Coping with a different child - Acceptance?	There's like in this like a no-go Zone. It's like a no-man's-land zone (laughs) between the two. You either are or you're not and then Barry fits a lot in the no go zone. So they actually call Barry a cupcake child”(P4)
	Maintaining/holding hope - developing hope?	They gave me confidence that I didn’t miss anything and that I was doing it right and giving Fran the support too” (P1)
	More than just a parent - forced identities?	“It's really difficult because I feel I'm not Josh or Barry's parents. I predominantly feel I'm their carer. There is this barrier between us ...It's very hard for me to hug Josh or hug Barry because of the amount of paperwork I have to do The amount of erm.. reaffirmation. (If you can sign that word... laughs) Reassurance, reoccurring with speech, listening, the care for the hearing aids, the... just general extra care I have to give them....(P4)

Discussion

This study aimed to explore hearing parents’ experience of having a deaf child with mental health difficulties. The findings highlighted the dual experience of having a deaf child and then a deaf child with mental health difficulties. As a result of this, the participants had to deconstruct and reconstruct how they have understood their deaf child and then their deaf child with mental health difficulties due to flawed information and high levels of uncertainties. They embarked on a new and unknown journey when their child was diagnosed as deaf and then a further journey into the unknown when their deaf child developed mental health difficulties. The unknown, uncertainties and not ?being acknowledged by others have contributed to the loss and ambiguity experienced by the participants. All participants have grieved, and they are still grieving on some level due to unresolved grief and ambiguous loss. Clinical implications included a need for clinicians to be mindful of unresolved feelings of grief and pain for hearing parents, even if a diagnosis of deafness and/or mental health difficulties was made many years earlier. The suggested interventions, such as ‘tempering mastery’ and ‘reconstructing identity’ or developing skills and strategies using solution focused approaches could be a way forward. It has been established that providing parents with a space to tell their stories is likely to lead to improved outcomes (Carter et al., 2007). However, this can often be difficult to schedule in busy NDCAMHS settings. It is worth considering the use of groups on an online platform for parents to share their experiences with each other, with a NDCAMHS clinician facilitating the group.