Child mental health and deafness

Rob Walker

Abstract

Mental health problems are more common in deaf children. Increased risk factors can be understood using a biopsychosocial model of mental health. Biological risk factors are more common in acquired deafness and perhaps some syndromes. These need to be identified and treated. The cultural model of deafness can be used to understand and manage many psychosocial issues and to prevent future mental health problems. Support for parents and early communication strategies are crucial. A comprehensive mental health assessment needs to incorporate the medical and cultural model of deafness and adaptations in the assessment process will need to be made. Further research is needed to establish which treatment approaches are most effective and how these may need to be adapted.

Keywords adjustment; (British) sign language; cochlear implants; communication; deafness; deaf culture; medical model; mental health; risk factors

Introduction

The assessment and treatment of mental health difficulties in deaf children is a complex, fascinating and challenging process. This brief paper aims to provide an introduction to the subject by raising a number of interesting issues which will hopefully stimulate further thinking, reading and debate. It starts by discussing the prevalence of childhood sensorineural deafness and the increased occurrence of mental health difficulties in this population. The reasons for this increase are considered by looking at the risk factors for mental health difficulties in all children, both hearing and deaf, and how these risk factors may particularly apply to deaf children. A biopsychosocial model of mental health is used to consider issues such as: severity of deafness, age of onset and age at diagnosis; cause of deafness; communication options; acceptance of and adjustment to the diagnosis; family issues and education and peer relationship issues. The importance of understanding the cultural model of deafness and using this alongside the medical model is discussed.

A holistic mental health assessment process which incorporates both models and draws together all of these factors into a diagnostic formulation and Care Plan is outlined.

Finally, issues around the diagnosis of specific mental health disorders in deaf children and treatment options are discussed briefly.

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Deafness: prevalence

Whilst recurrent conductive hearing loss can have a significant effect on children's language development, learning and behaviour, this paper focuses mainly on children with permanent sensorineural hearing losses (SNHL). One in 1,000 children in the United Kingdom is born with a permanent degree of hearing loss (hearing level in the better ear more than40 dB averaged over 0.5, 1, 2 and 4 kHz) and 50–90% more children are diagnosed by the age of nine years, so that 11 in 10,000 three-year-olds and 21 in 10,000 nine to sixteen-year-olds have hearing losses greater than 40 dB. Profound (95+dB) hearing loss is found in 2.7 per 10,000 three-year-olds and 4.4 per 10,000 nine to sixteen-year-olds.

Prevalence of mental health difficulties in deaf children

Research suggests that mental health difficulties are one-and-a-half times more common in deaf children than hearing children. Table 1 shows the risk factors for mental health difficulties in **all** children.

It can be seen that many of these risk factors are particularly common in deaf children, which explains the higher rate of mental health difficulties. The risk factors can be thought of as biological, psychological and social. The biological factors are primary disorders resulting directly from the cause of deafness. These risk factors cannot be prevented, but if correctly identified and managed their impact can be reduced. Other risk factors might be understood as secondary psychosocial factors resulting from the effects of deafness on other areas of the child's development and the way in which the deafness is accepted, adjusted to and managed; i.e., coping strategies used by the child, their family and professionals, some of which may be more helpful than others. These risk factors can not only be identified and managed but can also be prevented by appropriate early intervention. For example, there is no direct link between deafness and parental mental health problems, but stress and isolation can lead to more serious anxiety and even depression if parents are not properly supported.

This paper argues that the cultural model of deafness provides a positive and helpful approach to understanding and addressing many of these psychosocial risk factors and thus preventing future mental health problems.

Assessment

Every deaf young person needs to be seen as an individual for whom each of these risk factors may be more or less important. Mental health workers undertake a holistic assessment which identifies both medical and psychosocial issues. Such an assessment needs to consider where the young person and family are at this particular time and why they are asking for help now. The first thing which must be considered is how to meet the communication needs of the young person and their family. A qualified sign language interpreter must be used with children who sign.

As well as the individual risk factors discussed above, the assessment also takes into account the fact that children live in systems, including their school, their family and the wider society. Underlying all of these factors are contextual and political

Physical health problems, particularly chronic or neurological illness
Communication difficulties
Parental mental health problems
Unclear or inconsistent discipline
Physical, sexual or emotional abuse or neglect
Educational failure
Specific learning difficulties
Prematurity, low birth weight and birth injury
Developmental delay
Family discord/parental conflict
Hostile or rejecting relationships and failure to adapt to changing needs
Discrimination, isolation and bullying
Peer rejection or deviant peer group

Table 1

issues such as changes in technology; e.g., cochlear implantation, and changes in educational approaches; e.g., inclusion. Often many professionals are involved in the care of deaf children and information needs to be gathered from multiple sources and perspectives. Sometimes professional opinion about the best way forward will differ. Assessment tools and questionnaires which are standardized on hearing children can be useful but need to be interpreted with care.

All of this information needs to be gathered together into a diagnostic formulation which identifies predisposing, precipitating and maintaining factors and which then informs an individual Care Plan to address these issues. Throughout this process, mental health workers will try to avoid the traditional polarization which can occur around deaf children and take a more helpful position discussing all of the options and uncertainties. A typical initial assessment might involve discussion of the following issues.

Deafness: severity, age of onset and age of diagnosis

Age at onset of deafness is crucial, particularly whether the onset is pre- or post-lingual; i.e., before or after the development of spoken language. Although children deafened post-lingually have the advantage of a varying period of exposure to spoken language, sudden post-lingual hearing loss in older children is devastating for them and their families and often needs specialist emotional support. Pre-lingual deafness presents more challenges to the development of communication. Even within this group, there are differences between those born deaf and diagnosed early and those deafened or diagnosed later.

The NHS Newborn Hearing Screening Programme started in 2001 and has been available nationwide since March 2006. More than five million babies have been screened (over 98% of the population) and more than 6,000 babies with bilateral permanent SNHL have been identified. The average age at which congenital hearing loss is confirmed has dropped from between 24 and 30 months to between two and three months. Infants who receive appropriate interventions before six months of age do much better in language development, social emotional development and family adjustment than those whose hearing loss is first detected after six months of age. Whilst the benefits of early detection and intervention cannot be disputed, consideration does need to be given to parental anxiety which results from a failed screening test, not only false positive tests (2%) but also the effect on attachment of very early diagnosis in babies who are deaf. It is important that subsequent early interventions are aimed at promoting emotional well-being as well as communication and education outcomes.

The degree of deafness is also important. Some research suggests that children with mild and moderate losses have more emotional difficulties than those with severe and profound losses. This may be because young people who are severely and profoundly deaf have better self-esteem and identity and stronger peer relationships as a result of their educational placement.

Aetiology: congenital deafness

The cause of deafness may be congenital or acquired. In 50% the cause of deafness is genetic and the deafness may occur in isolation or as part of a syndrome associated with other medical problems. In the majority of genetic causes, inheritance is autosomal recessive, which crucially means that the family has no previous experience of deafness. The commonest genetic cause is Connexin 26, which is responsible for 50% of recessive non-syndromal deafness.

Cytomegalovirus (CMV) is the commonest infectious cause of congenital SNHL and affects 3–5/1000 newborns in the UK. One US study estimates 21% of hearing loss at birth and 25% in four-year-olds is caused by CMV. One-third of affected women pass on the virus to their unborn child but 90% of these newborns will be asymptomatic. However, both the symptomatic and asymptomatic forms of congenital CMV (cCMV) are associated with hearing loss which can be unilateral or bilateral and may be progressive. In the USA, 6,000–8,000 infants per year will have clinical manifestations and 75% of these will have SNHL. Some children with cCMV have suddenly lost residual hearing at age four or five and cCMV may present with hearing loss months or years after birth. In addition to deafness, cCMV is often associated with other physical problems, including visual impairment, cerebral palsy, feeding difficulties, developmental delay, learning difficulties particularly dyscalculia and epilepsy. Autism and behavioural issues, including problems with attention, seem to be more common, as well as sensory integration problems.

Congenital Rubella is now very rare, but given the current concerns about poor immunization levels in a generation who are now approaching child-bearing age, there is a worrying possibility that it will become more common again.

Syndromes

More than 300 forms of syndromal deafness have been identified. The commonest autosomal recessive syndromes are Usher Syndrome, Pendred Syndrome and Jervell and Lange-Nielsen Syndrome. Autosomal dominant causes of SNHL account for 10% of genetic causes, the most common being Waardenburg Syndrome, where usually, but not always, there is a family history, and Branchio-otorenal Syndrome.

Some syndromes seem to be more commonly associated with mental health difficulties, and the possibility of particular

behavioural disorders being associated with particular syndromes (behavioural phenotypes, as in Fragile X) merits further investigation. Often it is the emotional impact of acute and chronic physical health problems which may require medical and sometimes surgical intervention which seems to be the cause. In Usher Syndrome, retinitis pigmentosa leads to blindness (loss of night vision and tunnel vision), and in Alport Syndrome, 85% of cases are X-Linked and 90% of males and 10% of females will develop progressive hearing loss, and 75% of males develop end-stage renal failure requiring renal transplant by age 30. Neurofibromatosis (NF-2) is associated with bilateral acoustic neuromas. Symptoms of deafness, facial weakness and unsteadiness may appear during childhood, and surgery to remove tumours can result in sudden total loss of hearing and facial palsy.

In CHARGE Syndrome, the combination of deafness, visual problems and developmental delay can produce complex social emotional difficulties, whilst in children with Pendred Syndrome, where progressive hearing loss occurs, 50% will also have hypothyroidism, which can have a direct effect on mood, learning and behaviour.

A number of syndromes are associated with dysmorphic features, which can lead to stigmatization and bullying due to differences in physical appearance: e.g., Waardenburg Syndrome, which is also associated with Hirschsprung's Disease, Treacher Collins, where cleft palate can also occur, and Goldenhar's Syndrome, where major surgery is often needed.

Finally, other syndromes have important clinical features which need to be considered, even though these do not have a direct effect on mental health; e.g., Long QT Syndrome in Jervell and Lange-Neilson Syndrome. Although it is very rare in the general population, it could be as common as I in 500 in the deaf population. This may be an issue in the prescribing of certain psychotropic drugs.

Aetiology: acquired deafness

Acquired causes of deafness include prematurity, post-natal infections such as meningitis, anoxia, ototoxicity and trauma.

Acquired deafness is also associated with additional difficulties, including learning difficulties, visual problems, motor and balance problems, epilepsy, and memory and concentration difficulties. In addition, parents of children with meningitis have a particularly traumatic journey. Their healthy child is first diagnosed with a life-threatening condition from which they then recover only to be diagnosed as deaf. The parents are then offered a cochlear implant and have to make a rapid decision about this because of the risk of cochlear ossification. Later, other sequelae of the meningitis may emerge.

Adjustment

Different causes of deafness occurring at different times in a child's development produce very different stories and different associated problems which young people and their families have to adjust to. Some conditions are very rare and families can feel isolated. Professionals may also feel unskilled to deal with these rare conditions and expert opinion may be hard to find. Information available through parents' support groups may be extremely important for professionals as well as families.

It is often important for young people and their families to understand the reasons for their deafness, not only for genetic counselling but also to avoid inappropriate guilt and blame which can be an issue. One important and challenging question is at what age should young people be made aware of possible complications of their condition, such as blindness in Usher Syndrome and renal failure in Alport Syndrome?

Families are very vulnerable and dependent on professional advice at the time of initial diagnosis. Support from other agencies, such as the National Deaf Children's Society, can be invaluable. Understandably, families who have no previous experience of deafness may be preoccupied and even overwhelmed by medical issues, but in many cases early introduction to the cultural model of deafness may help their adjustment and reduce the chances of deaf children developing future mental health problems.

Deaf culture

Rather than seeing deafness as a medical issue and themselves as disabled, most Deaf adults see themselves as a cultural and linguistic minority with their own history, customs, organizations (social and sports; local, national and international) and language, which is British Sign Language (BSL) in the United Kingdom. BSL is a full language, and signed languages are as different in different countries as spoken languages are. Cultural Deafness is often identified by the use of a capital 'D' to distinguish it from audiological deafness, and indeed it is possible for those who are not audiologically deaf, particularly hearing children of Deaf parents, to be part of the Deaf community.

Whilst some may dispute this cultural view of deafness, it is important to consider the World Health Organisation (WHO) definitions of disorder, disability and handicap. Deaf people clearly have a disorder of their hearing and are disabled in the sense that they cannot hear as well as other people and this may affect the development of speech to a greater or lesser extent. However, it is essential to differentiate between speech and language and to realize that Deaf people are able to fully communicate in their native sign language. Deaf people do not have a communication disability or indeed a disorder of communication, but they are handicapped by society's failure to provide for their communication needs in the same way that someone who is physically disabled and unable to walk is handicapped by a lack of wheelchair ramps. In Martha's Vineyard in the late 19th and early 20th century, deafness was so common that hearing people as well as Deaf people learnt to sign and Deaf people were fully integrated into society. This demonstrates nicely how a cultural model of deafness can raise expectations and aspirations for deaf young people.

However, deaf children are different to Deaf adults in that most are not yet part of the Deaf community. Historically, the majority of deaf children have grown up to join the Deaf community and, despite changes in technology and education, it seems likely that many deaf children will still grow up to use sign language and many will join the Deaf community and find support in being part of this group. Early exposure to Deaf culture, particularly contact with Deaf adult role models, may help deaf young people to develop a positive identity and have a positive effect on their self-esteem.

Unlike other cultures, however, for most deaf children who are born into hearing families, Deaf culture is transmitted through contact with Deaf peers and Deaf adults and not through family. Previously, attendance at a Deaf school would be the way that many deaf children joined the Deaf community. Some hearing parents of deaf children will embrace this journey and become part of the Deaf community themselves whilst others will decide to avoid this route, but this situation may change when the child becomes older and able to make choices of their own.

Deaf children in Deaf families

Deaf children with Deaf parents do much better than deaf children of hearing parents, both socially and academically, even allowing for the fact that they have fewer additional difficulties. This demonstrates that it is not deafness *per se* that causes the difficulties which many deaf children experience, but the way in which the deafness is managed. This difference can be linked to Deaf parents' acceptance of their deaf child and particularly to the effectiveness of early communication. It lends support to the importance of early communication, but more importantly it provides evidence that deaf children can develop age-appropriate language and communication, provided that they are exposed to sign language. In this sense, it can be argued that sign language is the natural language of deaf children; i.e., the language which they acquire through exposure in the same way that hearing children acquire their 'mother tongue,' and not a language that has to be taught in the way that hearing children learn foreign languages.

Communication

Despite the evidence from Deaf children of Deaf parents, the issue of communication choices for deaf children remains controversial and much of the evidence available is contradictory. Medical and educational interventions are often aimed at the development of spoken language, and early access to sign language is often discouraged. Communication options do depend on level of deafness, but for many the development of age-appropriate spoken language will be delayed, and this lack of early communication will have negative consequences on issues such as attachment and reciprocity, incidental learning, and divided attention and shared attention. Early language also affects other cognitive processes, such as symbolic play and theory of mind development. There is no evidence to support the view that sign language interferes with development of oral language, and several studies have demonstrated that children who receive early manual training are actually more advanced in terms of early cognitive, social and academic achievement and these gains are maintained over the school years.

Previously, 90% of deaf children went on to use sign language as adults. There is a need to identify whether this number has changed with the introduction of cochlear implants and also the way in which these young people use sign language, but it seems likely that a significant majority will still use some form of sign language. The ideal outcome for most deaf children would be bilingualism, with the ability to use both spoken and sign language and to choose between the two in different situations. This is by no means an easy option; hearing parents will need support in learning a new language and there will need to be changes in the way many teachers are trained and more involvement of Deaf adults in education.

Cochlear implantation (CI)

The outcomes for CI in terms of improvement in spoken language and literacy are positive but they are also variable and unpredictable. There is limited evidence on psychosocial outcomes of cochlear implants. Parents have to be given realistic expectations prior to implantation and parents of implanted teenagers have reported ongoing concerns, particularly about progress in secondary school and long-term support and management of the implant systems. Whilst some implant teams continue to pursue an oral approach; e.g., using Auditory Verbal Therapy, other teams and researchers are moving towards encouraging more natural, relaxed communication and the use of visual strategies including signing to support the development of spoken language and literacy. They are also encouraging the use of home language for families who do not have English as their first language. Whilst their initial approach is to provide Sign Supported English in order to promote the development of spoken English, the role of BSL within this new 'total communication' is still open to debate. This approach sits much more comfortably with the evidence that supports the early use of signing in promoting the emotional well-being and mental health of deaf children. It also provides children and families not only with better early communication but also early exposure to sign language for those who later need or choose to go down a communication route which relies more heavily on BSL.

Education

In the last 20–30 years, inclusion and cochlear implantation have led to major changes in the education of deaf children. However, a recent NDCS study found that only 37% of deaf children achieved five A* to C grades at GCSE compared to 69% of their hearing peers, and for the first time the number of deaf children reaching this level fell by 2.4%. There is increasing concern about the support offered to implanted children in mainstream school, particularly at secondary level, and ongoing debate about the role of sign language in deaf education. Access to a Deaf peer group and Deaf adult role models is beneficial for social emotional development, but difficult to achieve in many areas without residential schooling or travelling long distances, both of which bring their own problems. An ideal solution is difficult to achieve and each child's needs have to be individually assessed. Deafness is a rare condition which can make it difficult to meet the needs of young people, particularly in rural areas. A Deaf Resource Base within a mainstream school is likely to be the best option for most, but some will need a specialist Deaf school and some will manage in mainstream with high levels of support. Encouraging hearing students and staff to sign and training in Deaf awareness are important. The education of children with a dual diagnosis; i.e., deafness and Autism or deafness and Learning Disability is particularly difficult.

Mental health disorders

Deaf children have the same mental health disorders as other children but they occur more frequently and may present

differently. Poor communication leads to low levels of emotional literacy and poor coping skills and deaf children often have difficulty expressing their feelings or describing their experiences and may act out their emotional problems through behavioural difficulties.

Emotional disorders, such as anxiety, may result from low self-esteem and issues with identity. Educational failure and peer group issues, such as isolation and bullying, can trigger anxiety in school. Family difficulties may also cause anxiety, which may be a direct result of communication problems or may be more difficult to resolve because of poor communication and misunderstanding.

Neuro-developmental difficulties, such as Attention Deficit Hyperactivity Disorder and Autism, are more common in deaf children but are often diagnosed late. There are particular differences and difficulties in diagnosing psychosis in young people who have limited communication or predominantly use sign language. Specialist assessment is recommended in these cases.

Interventions

Therapeutic interventions need to be delivered in a supportive communication environment. Non-verbal and creative therapies may be particularly helpful. Initial work on emotional literacy and emotional regulation is often necessary before more specialist therapies can be used. Family Therapy and systemic work are often useful, whilst interventions such as Cognitive Behavioural Therapy and Eye Movement Desensitization Reprocessing may need to be adapted for use in deaf children and further research is needed in this area. Medication is used when appropriate, but potential side-effects need to be carefully considered, particularly in those with additional physical health problems. ◆

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Practice points

- Mental health problems are more common in deaf children.
- Medical causes need to be identified and treated.
- The cultural model of deafness should be incorporated into the assessment process and used to manage current difficulties and prevent future mental health problems.
- The early use of good communication including sign language protects mental health and may support spoken language development and literacy.
- Standard assessment tools need to be interpreted with caution.
- Qualified BSL interpreters with mental health experience should be used for children who sign.
- Referral to National Deaf CAMHS for consultation and possible assessment should be considered in complex cases.