Mental health problems in deaf children

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Summary Children with early onset, severe to profound deafness are more vulnerable to mental health problems than their hearing peers. The key risk factors are developmental delays associated with early communication deprivation, CNS disorders associated with specific causes of deafness and abuse. Early psychological support to families and a wide range of communication options are crucial components in preventing mental health problems. Clinicians working with deaf children need to be sensitive to their communication needs and if necessary use British Sign Language (BSL) interpreters. Deaf children can benefit from a wide range of mental health interventions provided by generic and specialist services.

2005 Published by Elsevier Ltd.

Practice points

- Effective early communication (spoken language and British Sign Language (BSL)) and support to parents could prevent many mental health problems
- Deaf children are more vulnerable to emotional and behavioural disorders and to autistic spectrum disorders
- The child’s preferred mode of communication must be used when assessing mental health problems, if the child uses BSL a trained interpreter should be used
- Mental health interventions must be adapted to match the child’s developmental level, visual means of communication such as drawing and role play are essential components
- Many deaf children experience significant delays in literacy, writing is often not a reliable means of communication

Introduction

Deafness comes in many forms. Many children experience intermittent hearing loss associated with middle ear infections and their sequelae. These children may have difficulties in concentrating but their hearing loss alone is unlikely to have a profound effect on their development. In contrast children with severe to profound (i.e. <70 dB

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harmful factors for mental health problems? Additional medical problems or impairments that interventions will each child need and will they have medical perspective, which specific medical intervention with deaf children and finally touches on service development and delivery.

Approximately 1:2700 children are born deaf. The prevalence rises to approximately 1:1000 with the addition of children with deafness acquired in the first year of life. The vast majority of these children (95%) are born into families without any previous experience of deafness. A significant proportion are likely to grow to join the Deaf community, a group of people who experience the world visually, use British Sign Language (BSL) and frequently experience discrimination and oppression. It is important to recognise that BSL is a language distinct from English, with its own syntax and lexicon which are very different from English.

The impact of early onset deafness on these children's development can be seen in social, psychological, cultural and medical terms. From a social perspective, how easily will parents adjust to their child's needs and to what extent will social structures ensure that any disabilities are minimised? From a psychological perspective, how will the child's deafness affect their language development and social and emotional development. From a cultural perspective, which children will make the transition from their parents' hearing world to the world of the Deaf community. Finally from a medical perspective, which specific medical interventions will each child need and will they have additional medical problems or impairments that are risk factors for mental health problems?

Medical aspects of deafness and child mental health problems

Deaf children are more likely to experience additional illnesses than hearing children. From a child mental health perspective, central nervous system (CNS) disorders are highly significant risk factors, increasing a child's risk of developing a mental health problem by six times. Deaf children are at greater risk of CNS disorders than hearing children, with rates of up to 15% for disorders such as cerebral palsy and epilepsy. CNS disorders are often linked to causes of deafness, such as the complications of severe prematurity, intrauterine viral infections such as cytomegalovirus (CMV) or rubella and bacterial meningitis in infancy. Some of the syndromal causes of deafness such as the CHARGE syndrome association or Goldenhaar's Syndrome also cause CNS disorders. Other disorders are linked to physical illnesses such as diabetes (congenital rubella), hypothyroidism (Pendred's Syndrome) and cardiac abnormalities (e.g. prolonged Q–T interval). Physical illnesses, not affecting the CNS, also increase the risk of mental health problems in children, both directly and indirectly.

Deaf children are also more vulnerable to a range of additional disabilities. Most studies suggest that approximately 30% of deaf children have additional disabilities such as visual impairment, motor impairments and learning difficulties. Careful evaluation of additional disabilities and effective remediation play an important part in ensuring a deaf child's well-being.

Social, cultural and psychological aspects of deafness

Parents respond in many different ways to the knowledge that their child is deaf. Their response is shaped by their previous experience of deafness. The vast majority will not have had any direct experience of deaf people and they are likely to experience a sense of shock or disbelief. However, those parents who have increasingly suspected that their child is deaf may experience an initial sense of relief that their suspicions were correct. Parents' experience is being profoundly affected by current changes in audiological practice. Historically deafness was ascertained either by health visitor screening combined with targeted investigation of high-risk groups, such as children who had been in neonatal intensive care, children of deaf parents or children with deaf siblings. For most parents there was a period during which they could adjust to their child before their deafness was confirmed. The introduction of neonatal hearing screening is changing all this. Increasing numbers of children are being diagnosed as deaf within the first few weeks of life, thus allowing earlier intervention. The benefits of early intervention are now well established. Ideally parents should be offered a wide range of options, including the early introduction of sign language, early aiding and oral–aural interventions and/or early cochlear implantation. However, processing this information
and managing the powerful emotions evoked by the diagnosis need careful professional support. It seems clear from the North American early intervention programmes that early intervention workers need good psychological skills and access to psychology and mental health services to optimise parental well-being and so the well-being of the deaf children.

A recent National Deaf Children’s Society (NDCS) publication provides a detailed account of the experience of becoming the parent of a deaf child. From this it is clear that most parents see the task of parenting a deaf child as both similar to and different from parenting a hearing child. Parents’ perceived differences centre around the communication needs of deaf children and associated difficulties in handling issues such as discipline, discussing emotions and sex. These problems are accentuated for parents of children with multiple disabilities but lessened for deaf parents who, understandably, seem to experience the process of parenting a deaf child as less stressful. NDCS’ research showed that parents perceive the support of other parents as extremely valuable and they also publish an accompanying CD-ROM with parents describing their personal experiences.

In optimal programmes (see Sass-Lehrer and Bodner-Johnson 2003 for details) a significant proportion of deaf children will develop age-appropriate language, social and emotional skills. However, the majority of deaf children growing up in the UK are likely to experience significant spoken language delays and those who use sign language are likely to be in environments where adults’ and peers’ signing competency does not match their developmental needs. Thus, many deaf children have difficulty in accessing developmental experience and, as a consequence, experience significant developmental delays. Three aspects of development are particularly relevant to deaf children’s mental health. Firstly, there is a growing body of research which shows that deaf children are vulnerable to significant delays in the development of metacognitive skills, or Theory of Mind. Metacognitive skills relate to children’s growing capacity to understand that other people think and feel differently from them. This capacity begins to emerge in the second year of life in hearing children and is well established in the majority of five-year-old hearing children and deaf children of deaf parents. In contrast, approximately 70% of deaf seven-year-old children will not have developed first-order theory of mind. This is almost certainly because they have had no or very limited experience of conversations about other people’s thoughts and feelings. For similar reasons deaf children are more likely to show significantly reduced emotional vocabularies, understanding and recognition of emotions and capacity to regulate their emotions. Finally deaf children are also likely to show delays in the development of consequential thinking. These delays and deficits predispose deaf children to mental health problems and mean that they have more limited coping resources.

Deaf children are more likely to experience academic delays than hearing children. Deaf children are particularly vulnerable to delays in the development of reading and writing. Clinicians need to bear this in mind when working with deaf children and young people. The naive assumption is that pencil and paper will be an appropriate alternative to talking or signing. However, many will not have effective literacy skills and the written English of BSL users can be mistaken for thought disorder, rather than written BSL.

Deaf children are also more vulnerable to all forms of abuse (emotional, physical, sexual and neglect). Deaf children are more likely to have difficulty in disclosing abuse because they may not have the language to describe the experience and their distress and because adults in their lives may not understand them if they use BSL. Furthermore, investigating authorities may find themselves paralysed when they try to investigate alleged abuse and, anecdotally, prosecuting authorities are more likely to decide not to pursue charges. Finally the experience of abuse may compound pre-existing developmental vulnerability. The National Society for the Prevention of Cruelty to Children (NSPCC) is currently developing approaches to reduce deaf children’s vulnerability to abuse.

Epidemiology of mental health problems in deaf children and young people

Deaf children and young people are more vulnerable to mental health problems than hearing children. The prevalence of mental health problems in community samples of deaf children is approximately 40%. This includes children with transient and mild problems. Deaf children have been estimated to be 1.5–2 times more vulnerable to mental health problems than hearing children. Extrapolating from the latest ONS (National Statistics Online) data, this would suggest that 15–20% of all deaf children have clinically significant mental health problems. This increased prevalence reflects an increased prevalence of both emotional and conduct problems. In addition deaf children
appear to be at greater risk of developing autism spectrum disorders and Attention Deficit Hyperactivity Disorder (ADHD). Children whose deafness is caused by factors that also cause pervasive brain damage, such as intrauterine viral infections, the complications of severe prematurity and neonatal meningitis, are more vulnerable to mental health problems generally but particularly to autism spectrum disorders and ADHD.

A range of factors such as communication method, parents’ communication competence and school type (residential versus mainstream) have been proposed as risk factors specific to deaf children. However, the research is equivocal as to how significant these are. The most convincing finding has come from a Finnish study. In Finland children receive bilingual educations in Finnish Sign Language and Finnish and parents receive high levels of support to develop effective FSL. Sinnkonen found that Finnish deaf children had the same prevalence of mental health problems as their hearing peers. However, as yet, this finding has not been replicated.

Assessing mental health problems in deaf children

The communication skills of the clinician assessing a deaf child have a major impact on the outcome of the assessment. In circumstances where clinicians are faced with communication barriers, either a deaf child with limited communication skills or a signing deaf child interviewed by a non-signing clinician, clinicians often feel anxious and use exaggerated, positive body language to promote engagement with the child. Paradoxically this can lead to children not disclosing distressing experiences and feelings. Clinicians need to bear two factors in mind when assessing deaf children. Firstly, they must ensure that the most effective linguistic communication possible is used. For signing deaf children this will mean working with a BSL interpreter, ideally one with experience of working with children and young people. Secondly, they must manage their own anxieties and make sure that these do not interfere with the assessment process. However, when working with an interpreter it is important to brief the interpreter prior to the assessment and to discuss the assessment after it has finished. The interpreter has direct eye contact with the deaf child and so may have picked up non-verbal information such as unusual features of eye contact and body language.

The clinician must bear in mind that BSL interpreters are trained to interpret for meaning. Children who have psychotic disorders or developmental disorders that affect language functioning, such as autism, may present disordered language which the interpreter interprets as meaningful when the features of the disordered language are diagnostic. Specific examples include clang associations in early onset psychosis:

’a 15-year-old girl presented with aggressive behaviour, behaviour strongly suggestive of auditory and visual hallucinations and disordered language. During a group session she signed: CHRISTINE HATES ELEPHANTS’.

Further analysis of this statement showed that all of the signs used contained the K classifier handshape, a key feature of BSL, and so could be understood as a clang association similar to clang association in spoken language. Equally children with autistic spectrum disorder (ASD) may show unusual features of sign language that are akin to neologisms in spoken language:

’a 10-year-old boy with childhood autism signed GOOD MORNING using the correct handshape (a thumbs up) but in the wrong place (at his hip rather than at his upper chest) and the wrong size (moving a few inches rather than across his chest)’.

Clinicians are often tempted to use teachers or parents as interpreters in clinical situations. Convenience and the fact that the child is familiar with the adult are common reasons for doing so. However there are significant pitfalls in this approach. Firstly, teachers and parents are not trained to interpret and may miss out vital information. Secondly, they may inhibit the child from saying what they really think. Thirdly, it prevents parents and teachers from reporting their own concerns. Fourthly, it may actively prevent children from disclosing significant information such as abuse.

Interpreters can also be useful in other aspects of child mental health assessments with deaf children. In family assessment interviews an interpreter can be used strategically to assess family communication. Many parents report no difficulties in communicating with their signing deaf child when at face value this does not ring true. Involving an interpreter in the initial phase of an assessment interview will give an indication of the potential for communication within the family. Withdrawing the interpreter can then give an indication of the current level of communication.
Most deaf children seem to be more visually aware than hearing children. It is always useful to have pens and paper handy and to encourage the child and clinician to draw the problem. Equally, role play can be very useful in clarifying events and the child’s perception and experience of events. Deaf children are more likely to experience delays in literacy and as a result writing is not a useful means of communication for most deaf children.

Mental health interventions

The whole range of mental health interventions can be used with deaf children and their families. However, a number of specific factors need to be borne in mind. Firstly, the child’s communication method and ability and the family’s communication competence. Secondly, the child’s developmental level. Thirdly, bearing in mind the range of developmental delays described, most deaf children need a period of psycho-education during the initial phase of individual therapy. The aim is to ensure that the child has a good understanding of emotions, Theory of Mind and other psychological substrates. Finally, therapists need to be prepared to make use of visual approaches (drawing, role playing, sculpting, etc.) in circumstances where children cannot access verbal (signed or spoken) approaches.

Inpatient settings

Communication and deaf awareness become even more crucial factors in inpatient settings. Not only do staff need to be aware of the communication needs of deaf children, so do the other children. Anecdotal experience of deaf children admitted to hearing child and adolescent units suggests that the response of unit staff and hearing peers varies widely. In some units, staff are excited by the challenge of working with a deaf child and make every effort to ensure that the child can access the environment by providing deaf awareness training, sign language training for staff and children with a signing deaf child and by using interpreters where necessary. The NDCS has published a very useful guide for staff in these circumstances. However, even in units that make every effort, there are major difficulties for deaf children in accessing the therapeutic milieu and in forming meaningful relationships with their peers. The National Specialist Commissioning Advisory Group has commissioned a specialist inpatient service for deaf children and adolescents. Cornerhouse is a six-bedded unit. All the staff, deaf and hearing, are trained to use BSL. The service uses a modified therapeutic milieu approach aimed at promoting the social and emotional functioning of deaf children using educational and therapeutic approaches. A recent evaluation has shown good outcomes, 80% showing significant improvements in functioning and very high satisfaction ratings from parents and teachers.

Service development and provision

Deaf children face considerable difficulties when accessing mainstream services. Towards Equity and Access, the forthcoming Department of Health guidance on modernising mental health services, highlights these difficulties and recommends steps that local services can take to enhance access. These include deaf awareness training for staff, ensuring telephone access through text phones and videophones and making use of local interpreting services. Specialist services have developed in response to these difficulties in accessing services. These include outpatient services in London at Cornerhouse Outpatient Service, National Deaf Services and linked inpatient services. Cornerhouse Outpatient Service also supports two child and adolescent mental health teams in York and the West Midlands, using a pilot study of videoconferencing, funded by the National Specialist Commissioning Advisory Group (NSCAG). This pilot project is in its early stages but initial findings suggest that deaf adolescents and their families can effectively access individual and family treatments using this technology.

Conclusions

Deaf children and adolescents are at increased risk of mental health problems. This is as a result of the interplay between a range of factors. Early provision of effective communication within the family goes a long way to preventing many of these problems. Clinicians working with deaf children with mental health problems need to be aware of their communication needs and of the developmental consequences of deafness. Local services need to make adequate provision to minimise these barriers and there is an ongoing role for specialist services that can provide skilled assessment and interventions for this disadvantaged group. Towards Equity and Access, the forthcoming Department of Health guidance on mental health services for Deaf people should go some way to ensuring
that deaf children and their families have access to
the services that they need.

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