REVIEW


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ABSTRACT

The aim of this paper is to review the development of Child and Adolescent Psychiatry (CAP) for the deaf and hard of hearing, compared to the general CAP in Europe. Risk factors and epidemiology are described. It addresses the heterogeneous and changing population, the technical development and the vulnerable services. The paper highlights factors complicating psychiatric assessment and treatment in this specialised field and explores the challenges for future development.

KEYWORDS

children, mental health, deaf, hard-of-hearing

Background

The need for mental health services for the adult deaf and hard of hearing was observed already in the 1960’s and special units, inpatient as well as outpatient, were established in a few European countries during the 1970’s.

The need for mental health services for children was generally first seen at the schools for the deaf. Child and Adolescent Psychiatric (CAP) units for this group were established in the late 1980’s.

Assessment and treatment in sign language was stressed but also knowledge about the impact of a hearing loss on the development of the child and the family life.
Concepts and Definitions

Defining and describing the population for these specialised services is open for misunderstandings. A common agreement in the field is that the group is very heterogeneous. The label D/deaf has different connotations in different countries and consequently divergent findings regarding incidence/prevalence of mental health problems are difficult to interpret. There are also national differences when it comes to the acceptance and use of sign language in the education and upbringing of deaf children as well as the position of the Deaf community in the larger society.

In general discussions the criteria are often not explicit concerning severity of hearing loss, age of onset, additional handicap etc. In clinical settings the population is most often defined as children with a prelingual hearing loss, congenital or acquired in the first year of life, on a continuum from a level where prescription of hearing aids is motivated to complete deafness. Children with additional difficulties are usually included in the clinical group. In this article we will use the label “deaf” in a wide meaning. Most of the specialised services also admit hearing Children Of Deaf/hard-of-hearing Adults (CODAs).

Risk factors for and epidemiology of mental health problems in deaf and hard-of-hearing children

The vast majority (>95%) of deaf/hard-of-hearing children are born into families with no previous experience of “deafness”. The parents’ ability to adjust to the child’s needs is crucial for the development of the child as well as the dynamics of the family. When sign language is not accepted, a large number of deaf children experience language deprivation to a greater or lesser extent with consequences for their cognitive, social and emotional development.

Even if the family learns and uses signs, the daily communication will be strained and the child may become an outsider.

Adequate educational facilities cannot always be found within reasonable distance and if the family cannot move, the child either has to commute for several hours daily between home and school or go to a boarding school. Ad hoc solutions in a local school are sometimes good enough educationally, but not always appropriate when it comes to social interaction with peers.

Many causes of deafness such as prematurity, intrauterine viral infections or meningitis in infancy are linked to risk for CNS (Central Nervous System) disorders. In congenital syndroms the hearing loss is often part of a multiple handicap. It is internationally well established that approximately 30% of deaf children have additional disabilities such as visual impairment, motor impairment and learning difficulties.\textsuperscript{1,2}

Epidemiological studies often show an elevated rate of mental health problems in deaf children compared to hearing children, with rates ranging from 15 to more than 60%.\textsuperscript{3} The varying results can probably partly be attributed to the choice of informants and the different research methods.

When pupils in units for children with hearing losses in Great Britain were compared with children in the school for the deaf, the prevalence of psychiatric disorders among the children (age 11-16) was estimated to be on the average 50 %.\textsuperscript{4} The authors, stressing its importance, used a questionnaire validated in the deaf population. They also carried out interviews with the children.

A Dutch study showed a 41% prevalence of mental health problems in deaf children (age 4-18) compared to 16% in a normative sample, using The Child Behaviour CheckList (CBCL, Achenbach, 1991) with parents.\textsuperscript{5} In a study
from Germany, mothers and fathers of deaf and hard-of-hearing children completed the Strengths and Difficulties Questionnaire (SDQ). The results showed that 36% of the mothers and 39% of the fathers scored their deaf and hard-of-hearing children above the cut-off score compared to 15% in a German representative sample.6

In contrast to the above cited studies, a Finnish study using Rutters-B questionnaire stated that the prevalence of mental health problems in deaf and hard-of-hearing children (21%) did not differ significantly from the prevalence among hearing children (16%).7 In this study teachers of children age 6-16 participated.

In a recent Swedish study SDQ questionnaires were completed by parents and teachers and presented to deaf children (11-18 years) in both written form and in Swedish Sign Language by using a computerized program.8 This study shows that hard-of-hearing children seem to do as well as a group as other children in the Swedish society. The differences in performance seem to occur within the group and between three categories of hard-of-hearing children based on the nature of the school attended and the preferred mode of communication. The mainstream students and the students in the special school for the hard of hearing had higher levels of rated mental health than did the students in the school for the deaf.

In Austria a sample of pupils (6-16 years) with hearing impairments of at least 40dB and normal non-verbal intelligence were studied.9 The children were assessed with a structured clinical interview and the SDQ questionnaire was administered to parents and teachers. Point and lifetime prevalence rates for any psychiatric disorder were found to be 32.6 and 45.3% respectively. There was a relation between having a lifetime diagnosis and the child’s ability to be understood within the family.

In a study with a multi-informant approach a prevalence rate of psychiatric caseness of 49% was found in Dutch deaf adolescents (13-21 years).3 Data was collected by questionnaires to parents (CBCL), and teachers (TRF, Teachers Report Form), semi-structured clinical interviews with the adolescents (SCICA) and expert ratings of dossier data. Low IQ, a signing mode of communication and a history of three or more physical disorders were associated with psychiatric caseness.

In summary, using different samples and measurements with children from different countries, 15% - 61% of deaf and hard-of-hearing children seem to have mental health problems in comparison with a rate between 15% and 16% for hearing children.3,5,6,7,8 The differences in sample, methods and culture probably explain the diversity of findings and further studies in the field are needed to understand some of the differences in the prevalence rate of mental health among deaf and hard-of-hearing children.

**Trends and development in General Child and Adolescent Psychiatry in Europe**

During the last 20-30 years, the period when deaf CAP has developed, there has been a major change in CAP praxis and priorities. CAP services are unequally distributed over Europe. The variation is even larger when it comes to CAP specialists.10

Psychosomatic problems and anxiety, irritation and bad mood are more common today among 15-16 year olds in general. Generally, girls report more trouble with anxiety and feeling depressed now than in the 1980’s.11

Epidemiological studies on children and adolescents from before 1960 are scarce or non-existent, thus making it difficult to know
which of the changes in the mental health field are true.\textsuperscript{12,13}

The prevalence and incidence of severe psychiatric disorders seems to be stable, but the theoretical framework and description of psychiatric problems has changed over time.\textsuperscript{14} The stress-vulnerability model has become an important way of describing the intricate patterns of synergy between the mind and the brain, the society and the person, the individual and the context he/she lives and thrives in.\textsuperscript{15}

Whether it is possible and/or appropriate to “label” children’s problems and/or to make valuable and reliable diagnoses in childhood has been the subject of an ongoing debate. From a diagnostic point of view, one can see the changing trends. If this means that patients today are different and come from other problem groups than before is uncertain. During the 1970’s enuresis was a common diagnosis as well as hyperkinesia, the 1980’s showed a strong trend towards relational and system diagnosis in many countries, whereas true depression, psychosis, eating disorders, obsessive compulsive disorder (OCD) and other classic psychiatric diagnoses became prevalent in the 1990’s and have remained so since then.\textsuperscript{16} At the turn of the century a new problem arrived - self destructive behaviour.\textsuperscript{17} Repetitive self-harming behaviour became a common cause for long stays in psychiatric hospitals and many visits in the emergency rooms. In the UK chronic fatigue syndrome was diagnosed, mainly unheard of in the Nordic countries. In the beginning of this century many children with severe traumas from war zones and migration populations were diagnosed with pervasive refusal syndrome.\textsuperscript{18}

The complex problems associated with acting-out symptoms have most likely led to a much more thorough assessment of these problems and a large proportion of this group is today diagnosed not only with conduct disorder (CD) but also with hyperactivity (AD/HD), depression, autism spectrum disorders and other diagnoses. Comorbidity in childhood and adolescence is a very common finding.\textsuperscript{19}

It is still true that serious mental problems are more common in children and youths living under poor, strained or otherwise difficult psychosocial circumstances.\textsuperscript{20,21}

Attitudes to mental health issues have changed. With a better understanding of the problems presented by the youngsters and their parents and teachers and a more refined assessment, a corresponding change has taken place regarding treatment. Today a wide variety of evidence-based psychopharmaceutical and psychotherapeutic treatments and many promising, not yet fully researched and/or evaluated, interventions are available.

The largest change in CAP tradition during this period is that it is now possible and accepted to acknowledge both genetic/biological and environmental/relational aspects at the same time, in the same presented problem, in the same person/system and at the best of times this is reflected in both diagnosis and the treatment with both multifactor aetiologies and multimodal treatments.

Factors complicating psychiatric assessment and treatment of deaf and hard-of-hearing children

- Communicative factors

If the child’s main mode of communication is sign language the hearing therapist must either be a fluent signer or involve an interpreter. If the child uses spoken language with technical aids the equipment must be functional and the room audiologically adjusted.
Families may think that they have no difficulties in communicating with each other, but when an interpreter is present it is often obvious that this is not true.

Language difficulties may be present even if a deaf child has had adequate linguistic stimulation from birth. The child may have a limited vocabulary and a meagre experience of conversations about emotions and relations.\textsuperscript{22}

A specific language disorder in addition to the hearing loss must be considered and can be very complex to distinguish.\textsuperscript{23}

Conversations between a professional and the child are always vulnerable to confusion and misunderstandings. Skilled interpreters must be trained to avoid covering up for fragmented or confused language significant for psychiatric assessment.

Visual approaches such as drawings, small dolls and other figures, role play, are very often beneficial and allow the child to be part of the interaction with a "voice"of its own.

Inevitably the adjustments needed to establish reliable communication are time consuming and sessions must be planned according to this.

- **Neuropsychiatric problems**

Many causes of deafness (prematurity, infections) are linked to neuropsychiatric problems and there is an overrepresentation of problems such as AD/HD and autism spectrum disorders in the group.\textsuperscript{24,25} This calls for careful assessment of neurological problems.

Problems with attention, hyperactivity and social interaction also have to be differentiated from the sequelae of lacking communication. Recent research on mentalizing ability in deaf children has stressed the relation between fluent communication between child and caregiver in the early years, but has also proven that a delay in theory-of-mind development is not necessarily connected to an autism spectrum disorder.\textsuperscript{26} A significant factor to observe is if the child is sociable and wants to communicate with others.\textsuperscript{23} Neuropsychiatric assessment thus cannot be properly made if the child has not had access to adequate linguistic stimulation and/or technical aids for some time and even then results have to be interpreted with caution.

- **Family and Social network**

Since the majority of deaf children are born into families with no previous experience of hearing loss, family interaction is inevitably affected. Parents may be depressed and feel helpless for a long time after the child has been diagnosed. Very often not all family members learn sign language well enough to be able to handle daily conversations with the child and consequently misunderstandings and communication breakdowns are frequent.

Secondary caretakers can be involved if the child attends a boarding school or if the parents are in need of support.

Migration during the last decades has had a large impact on the CAP work. The family/child may be severely traumatised and without mutual communication the trauma remains unresolved. The child may be deaf from untreated illness and in many cases habilitation services and schooling have been minimal or non-existing. Cultural differences in child-rearing and conception of disabilities must be handled. When an interpreter is needed sometimes two interpreters are present in the room (sign language and national language).

- **Centralised services/Professional network**
Specialised services for the deaf/hard of hearing are necessary since the competence to handle the complexity of the population cannot be expected from single professionals or local units. A multidisciplinary team is needed both for assessment and treatment.

In addition to professional skills required in general CAP the staff must have appropriate language skills and cultural awareness.

Centralised services calls for cooperation with several institutions and external professionals both within and outside the field of “deafness” in a large geographical area. The specialised team must then provide consultations and information to external caregivers.

Outreach services are needed when families live far away from the clinic.

**Development of technical aids**

In addition to more advanced hearing aids a number of other devices have entailed important openings for deaf people, but also for professionals working with the deaf. Text telephones, introduced in the final decades of the last century, gave deaf individuals a channel for direct distant communication with other deaf persons and speech - text relay services opened ways to contact the hearing world. E-mail, webcams, chat forums and social media made communication even easier. Mobile phones with SMS, MMS and videophones gave a deaf as well as a hearing person the chance to be continuously available online by visual means.

For professionals videorecordings, videoconferences and telemedicine have become new tools for assessment and treatment particularly when patients and colleagues are physically distant.

**Factors complicating CAP work in deaf parented families**

When hearing children of deaf or hard-of-hearing parents develop mental health problems a number of special factors need to be considered.

Communication is a central issue. If both parents are signing and use sign language in daily interaction with their children it is well known that the children learn this language from birth in a very natural way. There are however a number of possible blocks to fluent communication within the deaf parented family and consequently to the child’s development. It is not uncommon that different communication systems are used within the family e.g. the parents use sign language with each other, but a mixed code with the children and the children use spoken language in their interaction. Quite often the children are perfectly able to understand what their parents express, but cannot answer in any qualified way and the parent-child discourse becomes restricted. If a deaf parent lives with a hearing partner imbalance of power is common and the parents can have difficulties in establishing joint parental authority.

CODAs are living in the margin of two cultures and there are similarities to the situation in immigrant families, where often the children have easier access than the parents to the culture of the major society. Most deaf parents are themselves children of hearing parents and may have been outsiders in the everyday life of their family. The deaf children/now parents may also have been to boarding schools. Thus they have not had full access to incidental learning and modelling of parental skills from their own parents and relatives and they may not have been able to read literature on child rearing issues due to poor reading ability. Child rearing thus becomes a transgenerational problem.

Deaf parents, who have been frustrated in the hearing society and do not feel confident themselves may idealise their hearing children, ascribing to them abilities beyond what can be expected at a certain age.
In connection with crises in the family CODAs often become more aware of their parents helplessness, not least in relation to different authorities and they can become very caring about the well-being of their parents.

The situation becomes even more complicated if a parent, due to personal difficulties, is incapable of giving priority to the child’s needs or does not even understand what the child requires.

Deaf parents often need more comprehensive information than hearing parents if a child gets a psychiatric diagnosis, e.g. depression, autism or AD/HD. Interventions that are more extensive are often necessary since deaf parents may need more support to fulfil their parental role when the child does not feel well.

In some cases, however, a limited intervention is sufficient: Well-functioning deaf parents sometimes need no more than confirmation that they are “on the right track” to gain self-confidence and thus power to handle their child.

**CAP resources for deaf and hard-of-hearing children in Europe 2011**

Sweden: Outpatient services since 1988, three regional units in Stockholm, Lund and Örebro. One unit in Göteborg closed 2009

Norway: Outpatient units in Oslo since 2007 and Trondheim 2008

England: Outpatient service in London since 1991, inpatient unit since 2000, outpatient services in Dudley, York and Taunton and several outreach teams.

Holland: Outpatient service in Leiden since 1987, inpatient unit since 1993, both closed 2008; outpatient services in Ede, Groningen, Amsterdam, Weert and Rotterdam

Austria: Outpatient service at Krankenhaus Barmerzigen Brüder, Linz since 1991, outreach services in schools for the deaf in Linz and Salzburg.


Spain: Outpatient services in Madrid since 2001.

In Denmark, Poland, France, Italy and parts of Germany single professionals or small teams serve deaf and hard-of-hearing children and their families as part of their clinical work at ordinary units for hearing children.

**Challenges and future development**

A number of challenges exist and can be foreseen concerning CAP for the deaf and hard of hearing. Even if adequate and equally spread CAP resources were to exist in all European countries in the future there are special issues that need to be addressed. The challenges are regional and/or national and concern the population, the school systems and expectations and living conditions in the heterogeneous and changing target group. Every region/country must tailor their specialised services so that they are suited for the population and in accordance with progress in the general mental health field.

**Vulnerable services**

Many of the services are very small, in many cases initiated by dedicated professionals and not always integrated/supported by the general health care structure. Professionals have to be continuously recruited and trained on the spot to secure the continuity of skills and make expansion possible. Once special units are established the influx of patients usually increases quickly.

**A changing population**

With the acceptance of national sign
languages in early intervention and education for the deaf from the 1980’s psychiatric assessment became more reliable. The consequences of language deprivation could be better separated from other factors influencing the child’s mental health.

After the introduction of Cochlear Implants in the 1990’s the population has changed. Now the absolute majority of deaf children in European countries receive a CI soon after the diagnosis. The outcome of the operation for language development varies. In most cases the child can be considered hard of hearing, rather than deaf, with spoken language as the main mode of communication. The marginal position of the hard-of-hearing person can however be quite stressful and mental health problems are not uncommon.

**Development of services**

Due to the changing population, the advanced technical aids and the new methods for assessment and treatment a continous development is necessary in the area of mental health and deafness.

A continous analysis of the needs, the strengths and difficulties in this heterogenous group is fundamental to maintain the quality of these highly specialised resources.

Methods for assessment and treatment developed for hearing children must be critically scrutinized and carefully adjusted for use with children with limited hearing. Results and outcomes should be interpreted and evaluated on the basis of knowledge about the impact of a hearing loss on the development of the child and the family life.

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